

The COVID-19 Wellbeing Study: Psychological wellbeing and perceptions of coercion amongst individuals intermittently advised to shield during the COVID-19 pandemic

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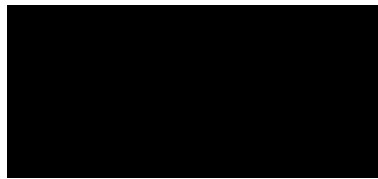
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Thesis Declaration Form

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## Overview

This thesis focusses on the psychological impact of the restrictions and protective measures intermittently adopted during the covid-19 pandemic and explores perceptions of coercion and psychological wellbeing experienced in relation to these measures for those classed as 'high risk' and advised to shield.

**Part One** provides a literature review forming an extended conceptual introduction to the empirical work presented in Part Two. This section offers an overview of the context of the Covid-19 pandemic, and explores the literature surrounding the social, ethical, and psychological implications of restrictive and protective public health strategies. Issues surrounding public adherence to measures are discussed, and the concept of perceived coercion in the context of applying restrictive practices for safety purposes is introduced.

**Part Two** presents a qualitative empirical paper exploring experiences of those classified as 'high risk' and intermittently advised to shield, focussing on the impact of these experiences on perceived coercion and psychological wellbeing. Findings indicate presence of perceived coercion and distress in relation to institutional expectations to reintegrate when restrictions and shielding advice was lifted. This paper forms a qualitative component of a wider Covid-19 Wellbeing Study.

**Part Three** offers a critical appraisal relating to the process of conducting the research in Part Two. This section highlights implications of conducting 'outsider' research and examines the challenges encountered during the recruitment phase. Considerations are discussed with regards to the researcher approach, and some personal reflections are offered on the findings and experiences of conducting research in the context of the pandemic.

## Impact Statement

The covid-19 pandemic presented a worldwide public health crisis leading many countries to adopt restrictive measures and preventative strategies to control the spread of the virus. The restrictions inherently posed numerous social, psychological and financial challenges to billions of people across the globe. This thesis offers a review of the social, ethical and psychological implications of these restrictive public health measures and an empirical exploration of the experiences and perceptions of those classified as high risk and intermittently advised to shield for their own safety. There is a particular focus on the impact of these experiences on perceptions of coercion and psychological wellbeing with consideration as to the additional impacts of safety structures such as the restrictions and official shielding support coming to an end.

This particular project seeks to represent the voices of a group underrepresented in the pandemic literature who have largely felt marginalised in society, this becoming magnified during the pandemic. The findings contribute importantly to the literature surrounding epidemics, pandemics, and health stigma, and offer the opportunity to better understand how the intermittent nature of the restrictions and shielding advice during an ongoing public health crisis has particularly impacted individuals at increased vulnerability to a virus that is still very much present. The project offers important considerations regarding the implications for policy-makers involved in the strategic management of future serious infectious disease outbreaks, which are thought to be inevitable given increasing globalisation and connectivity. Understanding the impact of the public health policies initiated and delivered during the pandemic for high risk individuals is crucial for informing

future responses by services that provide physical and mental health care, and highlights the particular importance of providing more accessible forms of this support for shielding groups.

Research examining perceived coercion has traditionally focussed on psychiatric populations in the context of the restrictive practices associated with hospitalisation, and demonstrates how higher levels of perceived coercion can detrimentally influence the felt distress, mental health trajectory and service engagement of this population. This project explores the concept of perceived coercion through a novel lens and offers insights into how such perceptions may arise in the event of restrictive safety structures being removed. In doing so, the project highlights gaps in both the psychiatric and non-clinical literature and identifies promising directions for subsequent research to address this.

With a view to pursue wider dissemination through eventual publication in an academic journal, this research project forms an important component of a larger Covid-19 Wellbeing Study that examines psychological wellbeing, perceived coercion, post-traumatic growth and coping in the context of the pandemic and associated public health restrictions for general public and healthcare worker populations across multiple countries. Much of this research is ongoing and will continue to illuminate the benefits and issues associated with the application, and withdrawal, of public health restrictions applied to mitigate the health consequences associated with serious infectious disease outbreaks.

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## **Part One: Literature Review**

The COVID-19 Pandemic: Exploring social, ethical, and psychological implications of restrictive public health strategies applied for infectious disease control.

## Abstract

This paper seeks to provide an overview of the current literature surrounding the psychological impact of the covid-19 pandemic and the accompanying preventive measures, such as lockdown and shielding policies. Although restrictive public health responses to infectious diseases intend to maximise public welfare by containing and preventing the spread, some have considered these strategies intrusive and coercive due to the limits they place on personal freedom and autonomy. This review will also explore public adherence, social, and ethical issues pertaining to the covid-19 restrictions, and introduce the concept of 'perceived coercion', a term typically used in relation to psychiatric populations when detained in hospital. Implications for the psychological wellbeing of high risk groups in the UK are discussed, and the potential for intermittent application and withdrawal of shielding instruction, guidance and accompanying practical support to give rise to perceptions of coercion will be considered. This conceptual review forms an extended introduction for the empirical work presented in Part Two, which aims to explore the experiences of individuals classified as 'high risk' and advised to shield during the covid-19 pandemic, with an emphasis on the impact of these experiences on perceptions of coercion and psychological wellbeing. The empirical work was conducted in conjunction with a wider scale research project, The Covid-19 Wellbeing Study (Ranieri et al., 2021), described towards the end of this paper.

## The emergence of Covid-19

The coronavirus disease 2019 (Covid-19), also known as the novel SARS-CoV-2, is currently the most significant global public health challenge. Covid-19 is thought to have originated in Wuhan, in the Hubei province of China, with the first case notified in December 2019. It is believed to be of animal origin; speculated sources include bats, snakes, minks, or asymptomatic human carriers (Cui et al., 2019; Ji et al., 2020). The virus is noted to be highly transmittable human-to-human via respiratory fomites and droplets (Guan et al., 2020), though our understanding of how covid-19 operates is continually developing as new variants that present with new characteristics and challenges emerge (Forni & Mantovani, 2021).

Infection with the disease can range from mild to severe pneumonia, ARDS (acute respiratory distress), which is associated with organ failure, and in some cases, death (Grygiel-Górniak & Oduah, 2021). Little was known about the virus itself during the initial phase of the pandemic; it was first largely assumed to be a simple transmissible respiratory condition.

Initially the most commonly reported symptoms included fever, a new continuous cough and shortness of breath, although there have since been numerous additions to the list, including but not limited to loss of taste and/or smell, fatigue, muscle ache, congestion or runny nose, sore throat, headaches, brain fog, nausea/vomiting and diarrhea. During the initial phase of the covid-19 outbreak, prior to the wider spread availability of testing across many regions, diagnosis of the virus was highly complicated and delayed by such variability in symptoms (Guan et al., 2020).

On March 11th 2020, the World Health Organisation (WHO) declared covid-19 a pandemic (Cucinotta & Vanelli, 2020). As the virus rapidly made its way around the globe, governments in affected countries and regions applied a number of restrictive measures in order to limit

and contain the spread. Although the particular containment strategies and the time at which they were initiated varied across governments, in the first phase these strategies generally included local and national quarantines or 'lockdowns', instructions to physically or 'socially' distance from others, to self-isolate if believed to be infected or to have had contact with someone infected, and instruction to refrain from non-essential travel. A number of countries, including the UK, implemented specific additional guidance for certain clinical groups deemed to be at higher risk of adverse outcomes if infected with covid-19. Generally this involved advice to stay home *at all times* and to physically distance from other household members to keep these groups safe from infection as cases continued to rise.

In December of 2020 the first covid-19 vaccine, developed by Pfizer-BioNTech, was given approval for use by the UK's Medicines and Healthcare products Regulatory Agency (MRHA). Subsequently, many countries around the world granted authorization for distribution and use of this vaccine, with approval of a range of alternative covid-19 vaccines shortly to follow, including those developed by Moderna, Johnson & Johnson, and Oxford-AstraZeneca.

Governmental approaches to the vaccine rollout varied. In the UK, older adults, care staff and other frontline healthcare workers were prioritised for receiving their first vaccine dose.

Since the initial vaccine rollout, by January 2022 all adults in the UK had been offered 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> (or 'booster') vaccinations, with individuals aged 75 and over to be offered a second 'Spring Booster' from April 2022. Plans regarding longer term immunisation strategies are under consideration, but currently remain unclear (Vagnoni, 2022).

Since the emergence of covid-19, the world has seen multiple variants with significant mutations that pose varying threats to the rate of 'spreadability', illness severity, and to the effectiveness of vaccines. As new variants continue to emerge and cases fluctuate,

governments across the globe have been required to intermittently impose, ease, and then re-impose restrictions, leaving the public in a perpetual state of uncertainty with regards to their personal health, the health of their loved ones, personal freedom, financial security and social activity (Rettie & Daniels, 2021). We continue to learn about longer term effects of infection with the virus, with several millions suffering lingering symptoms sometimes lasting more than 6 months following recovery from initial infection (Groff et al., 2021). This includes patients who have been hospitalised with covid-19, but also those who experienced mild symptoms during infection. This phenomenon has come to be known as 'long covid', and can include symptoms of mild to severe fatigue, chronic breathlessness, chest pain, persistent loss of taste or smell, and cognitive changes including brain fog (Cha & Baek, 2021; Groff et al., 2021). Given the threat long covid poses to quality of life, fear of contracting the virus has extended far beyond those who are known to be at an increased risk of adverse consequences.

In early 2022 the UK Government strategy shifted to 'Learning to Live with COVID-19', lifting all legal restrictions associated with the virus, including the requirement to self-isolate following a positive covid-19 test (Cabinet Office, UK, 2022).

Although much of the mental health literature relating to the pandemic explores fears surrounding exposure to the virus itself, there has been increasing focus on the impact of the public health strategies intended to contain the spread of covid-19. The restrictive measures and vaccine rollout has been highly controversial across society, and although it is understood that the majority willingly complied with these measures, many responded with scepticism and refusal to adhere to the rules and guidelines (Office for National Statistics, 2021). This contributed to significant societal conflict resulting from, and perpetuating,

widespread misinformation regarding the origin of covid-19 and the safety of the vaccines.

This paper will explore some of these issues and consider how they intersect to contribute to the complex ways in which governmental responses to the pandemic were perceived and experienced by those affected, and in particular, by those classed as high risk and advised to shield.

### The UK Shielding Policy

The UK prime minister announced the first national lockdown on 23<sup>rd</sup> March 2020, by which there were 6,650 confirmed cases and 334 covid-19-related deaths in the UK (Rawlinson, 2020). From this date, all non-essential shops and services were closed or moved to operate online and citizens (except key-workers) were instructed to stay home and work from home, only leaving the house to buy essential groceries or for one hour of daily exercise. Key workers included healthcare professionals, police, delivery drivers, firefighters, supermarket staff, and workers from other essential services.

The government set out to identify a list of those most at risk of becoming seriously ill if infected with covid-19 with a view to provide targeted advice and support to these groups. Those added to the list were deemed 'clinically extremely vulnerable' – now more generally and henceforth referred to as 'high risk' - and were advised to stay home *at all times*, avoiding all non-essential contact, and minimising time spent in communal areas at home if living with others. This included using separate bedrooms and bathrooms where possible. This came to be known as 'shielding'.

The initial list of conditions indicating the need to shield was signed off by Chief Medical Officers across the UK, and mainly included individuals with a single underlying disease, such as diabetes or specific types of cancer. Approximately 2.2 million (Office for National

Statistics, 2020) people were initially identified as high risk, and were advised by letter or text to shield until otherwise instructed. As such, those considered high risk were given priority slots for online grocery shopping, medication delivery and other essential services to support them to stay home. However, because identifying all high risk individuals was a complex and challenging endeavour requiring an extensive data search across healthcare settings (Lasseter et al., 2022; National Audit Office, 2021), there were many delays reported in identifying, communicating and supporting these groups to access this additional support (National Audit Office, 2021). Contributing to this were the inconsistencies in the official letters and texts sent out to people with underlying conditions, with numerous reports of patients given high risk status shortly having their status revoked via official messages from Gov.uk, often without patients' GP's knowledge (Torjesen, 2020).

An additional subset of individuals with other health conditions, pregnant women, and those aged 70 and above were identified as being at 'moderate risk'. Research published in 2021, however, has shown the highest risk of covid-19 mortality to be related to older age (Dessie & Zewotir, 2021). Although these additional groups were also advised to stay at home through public communication platforms, they did not receive official advice to shield and did not gain access to additional supports offered to high risk groups to enable their staying at home during the first phase of the pandemic despite their level of risk. It was not until February 2021 that the government extended the high risk status to include another 1.7 million UK residents. This was based on findings using the QCovid risk prediction model (Clift et al., 2020), which informed development of a new assessment tool that considered multiple factors to calculate an individual's risk of becoming seriously unwell if infected with covid-19. This included age, ethnicity, BMI, specific health conditions, ongoing treatments, and took into account a person's postcode as a measure of socioeconomic deprivation, known to be



linked to severity of illness if infected (Wise, 2021). This enabled access to additional support for facilitating shielding that these groups had not been offered during the initial phase of the pandemic.

Studies using forecasting and modelling predicted that the shielding policies should be effective in safeguarding those at increased risk from covid-19 throughout each shielding phase (Neufeld et al., 2020; van Bunnik et al., 2021; Weitz et al., 2020). Research into the actual effectiveness is sparse, however, a UK report examining the effect of the 12-week targeted shielding on the reporting of a positive test or covid-19 symptoms during the initial phase of the pandemic suggested that the shielding guidance reduced the probability of covid-19 symptoms/confirmed infection by around 4.2% (Kumari et al., 2021). Shielding was most effective for those in the highest covid-19 risk groups, with a 10.7% difference between individuals who received a letter instructing them to shield compared to those who did not. Although the findings support that shielding could be effective in reducing the likelihood of reporting covid-19 symptoms or a positive test, this study could not account for the extent to which guidance was strictly followed by those who received shielding instruction.

With the various phases of the pandemic, the shielding guidelines and support to enable them fluctuated. The communication of the UK shielding policy was heavily criticised for lacking consistency and being difficult to follow throughout the pandemic. A UK study involving 204 people officially advised to shield found that 20% of survey respondents did not agree that they had received all information required to inform their shielding behaviour, with 24% of respondents believing they had not fully followed the advice related to shielding (Lasseter et al., 2022). Of the 13 respondents invited to partake in a follow-up interview, all reported they had not fully adhered to all shielding recommendations. Instead, more a

spectrum of shielding behaviours adapted to participants' personal circumstances was evident. For example, where perceptions of risk were outweighed by the felt detriment of being trapped indoors, or by a deterioration in physical health due to lack of exercise, some participants reported adjusting their behaviour to allow for leaving the house for exercise. There were also participants who reported being practically unable to follow advice to shield from others in their household, such as dependent children who were not shielding. This emphasises the personal challenges surrounding the intermittent shielding guidance received by those classed as high risk.

It is important to highlight the fundamental distinction between shielding guidance and the lockdown and self-isolation legislation. The latter practices comprised a legally enforceable set of rules put in place to protect and ration NHS resources, and to protect others as well as oneself from contracting covid-19. Although the entire UK public, including high risk groups, were required to abide by lockdown and self-isolation laws, the additional restrictive recommendations communicated to high risk groups were framed as *advice* solely to keep oneself safe from others. We may consider this as, in its essence, a behaviour change intervention targeted at particular at-risk patients, giving space for personal choice in the extent of adherence to the health-related behaviour guidance.

## **Public Health Containment Measures**

### *A brief history*

Despite continuous scientific and medical advances, it has long been known that the risk of dangerous infectious diseases escalating to epidemic or pandemic level is growing (Antràs et

al., 2020). Given the rise in globalisation and connectivity, it is now possible for a virus to spread from one side of the globe to the other in a matter of hours, with potential to spread all over the world within a few days. The practice of quarantine has been the keystone of organised systematic responses to infectious disease outbreaks since as early as the 14<sup>th</sup> century (Tognotti, 2013).

Organised responses to infectious disease control notably began during the 'Black Death' plague epidemic between 1347 and 1352 (DeWitte, 2014), a disease estimated to have taken the lives of between 14-15 million people across Europe. Medicine was ineffective; they quickly learnt that the only way to elude infection was to avoid contact with contaminated objects, animals, and people infected with the virus. Rapid, firm implementation of restrictive measures, including denying access of 'strangers' and merchants into cities and separating the infected from the healthy through use of make-shift camps, was enforced by police and other authorities in many city-states (Philip & Ziegler, 1998). In 1348 the Venetian government established the world's first official quarantine system, whereby ships, cargoes and individuals entering Venice were held for up to 40 days before entering. In 1663 the first English quarantine policies were drawn, similarly allowing confinement of arriving ships with suspected plague-infected individuals on board.

Famously, church leaders in the small English village of Eyam implemented a particularly stringent local quarantine during a plague outbreak between 1665-1666 to protect nearby villages. Surrounding villages supplied Eyam with food and other essentials, for which residents left their money in troughs of vinegar, believed to kill off disease, much like today's alcohol-based sanitiser. Families were instructed to bury the dead as quickly, and as near to the site of death, as possible to mitigate disease spread from corpses. Church services were

held in open-air spaces to reduce the spread. Although considered an incredible act of collective self-sacrifice for the effective prevention of plague spread to surrounding neighbourhoods, yielding important implications for the management of future epidemics, the outcome was devastating for residents of Eyam. It is believed that only approximately 24% of the population survived (Massad et al., 2004).

Over the centuries, quarantine as a method of disease control has continued to be adopted by many governments in a variety of forms in response to a range of infectious diseases. During the Spanish Flu pandemic of 1918-1919, authorities in major Western world cities established additional containment strategies, similar to those we see today, suspending all public gatherings and imposing the closure of schools, churches and theatres, in order to limit the possibility of contact with the virus. The first pandemic of the 21<sup>st</sup> century was that of SARS (Severe Acute Respiratory Syndrome) in 2003, a disease originating in the Guangdong Province of China. In response to the threat to worldwide public health, the traditional containment measures discussed above were resurrected, with the countries hit hardest by SARS (including China, Singapore and Canada) imposing a variety of preventative strategies. In Canada, people who might have had SARS exposure were asked to voluntarily self-isolate. Authorities in China took a more stringent approach. Buildings were cordoned off by the police force, organised checkpoints were set up on roads, and in some cases webcams were installed in private homes to ensure compliance with quarantine. In some areas laws were passed that meant those who violated quarantine would be subject to extremely severe punishments; this included the death penalty (Tognotti, 2013).

It is only relatively recently that the need to increase protections for certain groups more at risk if infected is documented to have been acknowledged by institutional powers. This

follows advances in knowledge surrounding the disproportionate impact of public health threats on some groups, dependent on the disease (Hutchins et al., 2004, 2009; Institute of Medicine (US), 1988).

### *Social and Ethical Issues*

Quarantine and other preventative public health strategies are effective ways to minimise spread of infectious diseases, particularly in absence of available pharmacological treatment. However, these practices inherently restrict individual liberties and have long been controversial, perceived by many as intrusive and coercive due to the threat they pose to freedom and autonomy (Atlani-Duault et al., 2020; Cetron & Landwirth, 2005; Tognotti, 2013). Despite the motivation to preserve public welfare, throughout history these preventative strategies have raised many social, economic and ethical issues. In every age in which they have been imposed, such measures have been accompanied by a level of suspicion, distrust, protests and riots by some proportion of the population (Tognotti, 2013).

### *Individual Liberties*

Individual liberty concerns our freedom to make autonomous choices about how we exercise those of our rights which lie outside the realm of government control, so long as no threat is imposed to the rights or safety of others in doing so (Collins English Dictionary, 2005; Reed Business School, 2020). The specific liberties granted by a government to its citizens with a view to protect human rights, such as the right to freedom of action, movement and speech, are often referred to as 'civil liberties'. In a state of civil liberty, citizens are in theory subject only to those laws established for the common good.

Significant infectious disease outbreaks present authorities with an ethical dilemma, whereby restrictive strategies to control spread and protect the population must be weighed up against the threat they pose to individual liberties, and are only legally justifiable by the prevention of harm from person to person through disease spread. In simple terms, this constitutes the ethical reasoning of John Stuart Mill's 'harm principle' (Matose & Lanphier, 2020; Mill, 2003). Under this principle, authorities may curtail individual liberties for collective and individual self-protection, and can impose on citizens a legal obligation to abstain from exercising personal liberties that may pose harm to others. Where there is potential for significant or life threatening harm simply through close proximity with others, imposing legal measures that limit this potential by restricting freedom of movement, and to some extent, freedom of action, such as social distancing and lockdown measures, is generally considered sufficiently justified by the harm principle (Matose & Lanphier, 2020).

Covid-19 posed a significant threat to the lives of those directly affected by the disease but also to those who might have been unable to access crucial healthcare in the event of the NHS becoming insufficiently resourced. As such, the UK government appealed to an important element of the British public's common interest in their attempt to publicly justify lockdown and accompanying strategies by placing a heavy focus in their campaigns on protecting the NHS from becoming overwhelmed with the slogan: 'Stay at home, Protect the NHS, Save lives'. Although potentially beneficial for motivating adherence to the measures, it is important to highlight that these slogans and the accompanying dominant narratives around adhering to covid-19 legislation to protect the NHS fail to accurately reflect the actual legal justification discussed above, namely, to prevent people from harming others.

### *Disproportionate Impact*

An important consideration on the stance that the harm principle justifies the restriction of liberties to prevent harm acknowledges that social distancing and lockdown measures can themselves cause other harms (Fairchild et al., 2020; Matose & Lanphier, 2020), a number of which will be discussed later in this paper. Such harms disproportionately affect those who are already most socially and economically vulnerable.

In addition to the disproportionate impact of infectious diseases on the health and mortality of people from marginalised groups (Strully, 2011; Yaya et al., 2020), the impact of isolation, quarantine, and other restrictions most significantly affect the liberty of people from lower socioeconomic groups and minoritised ethnicities through further limiting already minimised access to opportunity, healthcare, financial security, and coping resources (e.g. community and family connection) (Gayer et al., 2020; Mattos dos Santos, 2020; Scobie & Whitehead, 2020). Public health strategies have also been seen to perpetuate stigma and discrimination against marginalised groups. Examples of this were documented during the Black Death, where Jewish people were systematically prevented from entering certain city-states (Ziegler & Platt, 1998). Parallels can be seen today, with reports of increased racist discrimination and attacks on people of South-East Asian people (Hahm et al., 2021).

## **Restrictive Measures and Psychological Wellbeing**

### *Previous Epidemics and Psychological Wellbeing*

A great body of literature from previous epidemics supports that public health strategies intended to limit transmission of infectious diseases, such as individual and wider scale

quarantines, can have a significant impact on the mental health of those affected (for a rapid review, see Brooks et al., 2020).

A wealth of research has been conducted with those required to quarantine during the 2003 SARS crisis, the majority reporting high levels of emotional disturbance during and following quarantine periods, including depression, stress, post-traumatic stress (PTS) symptoms, insomnia, emotional exhaustion and anger (Hawryluck et al., 2004; DiGiovanni et al., 2004; Reynolds et al., 2008; Lee et al., 2005; Maunder et al., 2003; Marjanovic et al., 2007, respectively). A study examining a large cohort of adults in Canada who were asked to quarantine during the SARS outbreak demonstrated that longer periods of quarantine was positively associated with greater PTS symptoms (Reynolds et al., 2008). Similar findings have also emerged from research conducted with people affected by the 2013-2016 Ebola epidemic and the 2009 Swine Flu (H1N1) pandemic (Jalloh et al., 2018; Braunack-Mayer et al., 2013).

The quantitative and qualitative research surrounding SARS, Ebola and Swine Flu show a variety of adverse responses to the quarantine experiences in those isolated due to infection, contact or for preventing exposure. Across a number of studies, participants' reports of their negative responses to these measures included feelings of nervousness, sadness, numbness, anxiety-related insomnia, grief, fear and guilt, with just some participants reporting positive feelings, such as a sense of relief (Reynolds et al., 2008; Braunack-Mayer et al., 2013; Caleo et al., 2018; Jalloh et al., 2018; Cava et al., 2005; Wang et al., 2011).

The experience of quarantine can come with lasting effects. Around 54% of participants in Reynolds and their colleagues' (2008) study continued to be avoidant of people coughing and sneezing long after their isolation period. Similarly, vigilant handwashing, avoidance of



crowded places, and general delay in a return to 'normalcy' are all behavioural changes participants of a qualitative study described to persist many months following quarantine periods (Chatterjee & Chauhan, 2020). Although in the context of a serious infectious disease outbreak these behaviours might be considered sensible and adaptive, the internal states that drive such vigilance and arguably life-limiting behaviours appear reflective of those involved in the maintenance of anxiety disorders including health anxiety, agoraphobia and obsessive-compulsive disorder. This is a concern particularly for individuals with mental health disorders whose recovery and relapse-prevention depend on regular exposure to the outside world and to social activities, including depression and a range of anxiety disorders. Research conducted in Honk Kong, however, highlights evidence as to some more positive impacts on wellbeing reported by the general public during SARS, including increased support from family and friends, and lasting positive lifestyle changes like increased exercise and prioritising relaxation (Lau et al., 2006).

Although some positive consequences of quarantine have been reported, overall the literature further supports the need for benefits to public welfare to be carefully weighed up against the possible costs to individual rights and consequential psychological wellbeing when considering the initiation of restrictive disease control measures.

### *COVID-19 restrictions and psychological wellbeing*

A rising body of literature is emerging regarding the psychological impact of the covid-19 pandemic and the associated restrictive measures imposed intermittently throughout it. However, as the pandemic is ongoing and restrictions continue to fluctuate globally, the

majority of published literature is focussed on wellbeing data collected during the earlier stages of the pandemic in 2020. Thus, our understanding of the longer-term impact of the pandemic and disease control measures is still limited. As we might expect, there are parallels between the current covid-19 literature and the evidence from previous infectious disease outbreaks.

With loneliness and social isolation acknowledged as some of the most probable psychological consequences of the restrictive measures, there was a surge of research exploring the impact on these factors during the initial phase of the pandemic. Multiple studies reported a significant increase in loneliness in the general public, and a marked reduction in the perceived quality and quantity of social relationships during the first wave (Buecker & Horstmann, 2021). Generally this perceived reduction decreased over time, possibly as many people adjusted to alternative ways to socialise within the constraints of the restrictions.

Loneliness has been associated with poorer mental health, increased mortality and a reduction in quality of life (Richardson et al., 2017; Beutel et al., 2017; Luo et al., 2012; Arslantaş et al., 2015), and although concerns around loneliness are usually associated with later life, younger populations are also experiencing loneliness at a concerning rate (Leigh-Hunt et al., 2017). Increased loneliness experienced as a result of the pandemic is positively associated with adverse mental health consequences (Pai & Vella, 2021; a systematic review). It is therefore important to hold in mind the role loneliness may play in the findings discussed here regarding psychological wellbeing during the pandemic.

A UK repeated cross-sectional longitudinal study examining the mental health of households before and during the initial phase of the pandemic found an overall increase in self-reported

mental distress compared with previous UKHLS trajectories, likely reflecting the impact of life in lockdown (Pierce et al., 2020). Relative to previous trends, psychological distress was particularly increased among those employed before the pandemic but subject to furlough, reduction in income, shifting to home working, and in those facing potential exposure through face-to-face work. Distress was more common in individuals from low income households, with higher ratings for those unemployed, in full-time education or other 'economically inactive' positions. This is in line with findings from research into past disease outbreaks which demonstrate similar socioeconomic inequalities (e.g. Scobie & Whitehead, 2020).

Another widescale UK study examined the trajectory of mental health symptoms and wellbeing during the first national lockdown (O'Connor et al., 2021). Data was collected at three timepoints during this period, and across each around 1 in 4 reported moderate to severe levels of depression. The mental health outcomes were generally poorer amongst people with pre-existing mental health problems and from socially disadvantaged groups. Reports of suicidal ideation increased during the initial weeks, particularly amongst young adults, with 14% continuing to report suicidal thoughts in the final wave of data collection in May 2020, compared to pre-pandemic norms of 11% for these groups. Respondents also reported on symptoms of anxiety and feelings of defeat and 'entrapment' during this period, although interestingly these symptoms significantly improved across the three time-points. Rates of positive wellbeing also increased on average across timepoints, which may reflect gradual adjustment to lockdown and to the uncertainty that was possibly heightened when restrictions were initially imposed.

Although the known risk factors for suicide have been exacerbated during the pandemic, including financial insecurity, isolation, depression, PTSD, suicidal ideation (O'Connor et al., 2021), the available evidence indicates that overall rates of suicide did not increase during the initial phases of the pandemic (Tandon, 2021). The long-term impact on suicide is not yet certain, though reports to date support that, contrary to expectations and media speculation, there have in fact been very slight reductions in overall suicide rates (Ahmad & Anderson, 2021; Appleby et al., 2021). This appears to follow a similar trend to data on suicide during historic public turmoil, such as during the major world wars, during which there was also reduction in suicide (Lester, 1994). Nonetheless, as the intermittent pandemic restrictions and their implications persist, the data must be continually reviewed to inform future responses to infectious disease outbreaks.

The short-term mental health consequences of the pandemic, including depression, anxiety, insomnia, and PTSD, appeared equally high across most countries affected by the covid-19 restrictions (Cénat et al., 2021). A systematic review and meta-analysis of studies from 14 different affected countries revealed that over 30% of participants developed anxiety and depression during the covid-19 pandemic (Chekole & Abate, 2021). However, there is also evidence that economically developing countries have been disproportionately affected, with greater proportions of the population plunging into poverty and longer term, more severe health and mental health provision consequences (e.g. Chen et al., 2021).

The evidence is clear that the covid-19 restrictions have had disproportionately adverse mental health consequences for people from lower socioeconomic backgrounds and minoritised groups (Gayer et al., 2020; Mattos dos Santos, 2020; Proto & Quintana-Domeque, 2021). The UCL Covid-19 Social Study demonstrated that thoughts around suicide

and self-harm and actual self-harm during the pandemic were increased among women, people at socioeconomic disadvantage, people from Black, Asian and minoritised ethnicities, and people with pre-existing mental health disorders (Iob et al., 2020). The exact reasons underpinning these disparities remain largely unclear, although are considered to be due to a complex intersection of factors relating to the impact of pre-existing societal inequalities for lower income and ethnically minoritised groups. This is thought to include factors further exacerbated in the context of the pandemic restrictions, such as inequality in access to healthcare and mental healthcare services, smaller and overcrowded living spaces, poorer working conditions, and increased levels of insecure employment for these groups; these factors largely considered, in turn, to be influenced by oppressive societal power imbalances and structural racism (Fortuna et al., 2020; Katikireddi et al., 2021). This has important implications for the future management of infectious disease outbreaks.

Lockdowns resulted in significant changes to daily living across the globe and created new barriers to physical activity for many citizens. A study examining data from smartphone wellness apps showed a 27.3% decrease in mean steps worldwide within 30 days of the WHO pandemic declaration, some regions dropping by up to almost 50% (Tison et al., 2020). It is well-established that exercise promotes physical and psychological wellbeing and that lack of it can precipitate and maintain poor mental health (Chekroud et al., 2018). As such, a multi-national study examined physical activity, mental health and wellbeing of adults living in the UK, New Zealand, Ireland and Australia during restrictions (Faulkner et al., 2021). Across all countries investigated, individuals who experienced a negative change in their physical activity from before to during restrictions reported significantly poorer mental health and wellbeing. A reduction in exercise can have serious health consequences for those with certain physical health conditions that require maintenance of physical activity to prevent

deterioration (Capodaglio, 2018), and many with such conditions are likely to have been included in the high risk classification.

### *'Shielding' and Psychological Wellbeing*

Awareness of ones' status as extremely vulnerable to covid-19 and the associated mortality risk understandably contributed to heightened anxiety and worry related to the virus itself among those required to shield (Lasseter et al., 2022; Sloan et al., 2021). Although crucial for ensuring protection of these groups, the shielding recommendations and parameters were highly challenging and life-limiting in many ways. Those who shielded were instructed to follow guidance far more restrictive than that administered to the rest of the public, with instructions not to leave the house for *any* reason other for essential medical appointments and to physically distance from other household members (Gov.UK, 2020). Although like lockdown experiences, it is likely that experiences of shielding varied depending on individual circumstances such as access to private outdoor space, household size, having a shielding companion, and financial stability, emerging evidence suggests that those who shielded may have been disproportionately impacted in terms of mental health consequences (Sloan et al., 2021).

The current body of evidence, albeit small, indicates a high proportion people shielding experienced a significant decline in their mental health, with reports of increased loneliness, depression, and anxiety (Gessa & Price, 2021; Lasseter et al., 2022; Sloan et al., 2021; Webb, 2021). However, factors influencing the impact on the wellbeing of those who shielded is bound to be complex, and the existing findings suggest effects extend beyond the direct impact of being physically restricted and socially confined. Research with older adults

shielding from covid-19 indicates that even after controlling for demographic characteristics and lack of social contact, older adults who shielded had a higher probability of reporting increased symptoms of depression and a reduced quality of life compared with those who did not shield (Gessa & Price, 2021).

Findings from recent qualitative research indicate that for some, being classed as high risk was felt to have provided a sense of acknowledgement and validation of the severity of participants' health conditions. The majority of participants thought the experience reinforced their felt resilience in terms of their ability to cope with the pandemic, and some reported feeling a reduction in the pressures of normal life combined with a reduced sense of missing out given that the rest of the public were under lockdown. However, many participants also described a sense of their social and self-identity becoming diminished, their lives suddenly determined by their new high risk label and its connotations (Sloan et al., 2021).

Although the high risk classification may have come from a caring position and a wish to protect those most at risk from covid-19, the concept of 'vulnerable people' vs 'non-vulnerable people' has potential to increase stigma and prejudice and perpetuate an 'othering' division. Vulnerability, by definition, is associated with emotional and/or physical weakness, and in Western society typically connotes lack of ability to fully care for oneself, others, or to contribute meaningfully to society (Perkins & Repper, 2020). Despite the intentions, the 'vulnerable' label is arguably problematic and can be potentially harmful for those clinically defined as such. In the context of covid-19, restrictive measures issued to the public through media platforms were given with one of the rationales being to 'protect the vulnerable'. In UK briefings by the Prime Minister the general public were frequently

commended for sacrificing normality by following lockdown guidance. However, for those classed as high risk, the sacrifices made for their own protection appeared less incorporated into the narrative portrayed by the government. It is important to consider how this may have shaped the experiences of those classed as high risk.

The pandemic has raised countless medical dilemmas and moral distress for managers of healthcare systems, which have become chronically overwhelmed. Due to limited resources, decisions regarding the provision of care were increasingly based on urgency, likelihood, and expected duration of benefit and improvement in quality of life following treatment (Dyer, 2021; Nicola et al., 2020). In the UK this had a devastating impact on equality and human rights laws in the context of medicine, whereby as a last resort there were many cases in which advance 'do not attempt cardiopulmonary resuscitation' (DNACPR) decisions were needed to be made for some groups, who under normal circumstances may not necessarily have chosen or required a DNACPR (Dyer, 2021; D. I. Jeffrey, 2020). Although there has been little empirical investigation into the effect this may have had on those potentially affected, this included some groups of those advised to shield (Bird & Wilson, 2022). It is important to consider how this may have further influenced the narrative that those with 'underlying health conditions' are in some way separate to the general public. We can imagine the role this might play in mental health consequences for high risk groups, in addition to witnessing a public wavering in adherence to the rules.

### **Adherence to Public Health Measures**

Whilst the evidence generally supports the use of preventative strategies like lockdowns for curbing the spread of covid-19 and shows general public support for these measures (Adam,



2020; Gunia, 2020), reports also indicate that full compliance with these measures varied. This poses a significant issue since the effectiveness of these interventions relies on unanimous complicity. Most countries that imposed lockdowns have seen some citizens fail to adhere to the restrictions, with some outwardly resisting the rules, often arguing that the restrictions violate their rights as citizens (Aaron, 2020; Chaudhary & Kumar, 2020). Across England and Wales, more than 42,000 fines for breaking rules were issued during the second national lockdown (Gillespie, 2021), up from approximately 15,700 during the first (National Police Chief's Council, 2020). This variability in adherence to public health measures has prompted research aiming to understand why some individuals may contravene the rules put in place to protect the nation.

Research conducted in France, a nation severely affected by covid-19, indicates a number of sociodemographic, personality and emotional characteristics predictive of adherence to lockdown measures (Brouard et al., 2020). Characteristics found to be positively associated with adherence included participants' age, conscientiousness and fear surrounding covid-19. Gender was also shown to be a predictor, with female participants significantly more likely to report compliance. Political ideological extremity was associated with poorer adherence, which is in line with research that those whose beliefs fall within ideological extremes are more likely to be distrusting of the government and its actions and more inclined to endorse conspiracy theories (Brouard et al., 2020; van Prooijen et al., 2015). We must note that these findings rely on self-reported adherence and may not capture the true picture. Nevertheless, these findings provide valuable insight into public 'misbehaviour' during lockdown periods, and begin to show the importance of individual differences in the way in which the guidance was received.

A larger scale international study examined how beliefs and attitudes about covid-19 predict adherence to public health measures (Clark et al., 2020). They found that belief in the effectiveness of the rules and concern for one's own health were both highly predictive of voluntary compliance with following public health guidance and encouraging others to do the same. These findings remained strong even after controlling for sociodemographic and personality characteristics; age, perceived personal vulnerability to covid-19 and trust in the government were factors of comparably little importance in predicting compliance with government guidance. The latter finding, however, contrasts with results from a study of European mobility trends, which demonstrated that regions with greater trust in their government decreased their mobility related to non-essential activities during lockdown significantly more than low-trust regions (Bargain & Aminjonov, 2020). This suggests a greater compliance with covid-19 restrictions in regions high in trust for their government; an important factor to consider in formulating public health responses to future infectious disease outbreaks.

Public variability in the willingness to receive the covid-19 vaccinations has also been evident. The success of the covid-19 vaccines in curbing the spread and severity of the virus depends not only on their safety and clinical effectiveness, but also on the scale of public acceptance (Sallam, 2021). It was estimated that for the vaccine to provide herd immunity it would need to be accepted by 55-85% of the population, dependant on country and infection rate (Kwok et al., 2020; Sanche et al., 2020). By the 7<sup>th</sup> February 2022, 91.2% of the UK population ages 12 and above had received their first dose of the vaccine, with 84.5% having received their second, and 65.4% their booster dose (GOV.UK, 2022). This leaves a sizeable proportion of the UK population (8.8%) who have not yet received a covid-19 vaccine. The UK citizens who have not received their covid-19 vaccinations, and who do not fall into the category of those

advised against vaccinations due various reasons such as allergy to the ingredients, are assumed to have chosen not to receive it for whatever reason, with some reported to remain 'very unlikely' to take the vaccine according to a 2021 survey (Ansell et al., 2021).

For a small group, vaccine hesitancy and avoidance is largely related to needle-phobia (Freeman et al., 2021; Love & Love, 2021). Surveys have also indicated a greater covid-19 vaccine hesitancy from some minoritised ethnic groups compared to people from a white ethnic background (Razai et al., 2021; Robertson et al., 2021). This has some serious implications, given the disproportionate adverse consequences of the pandemic for these minoritised groups, and emphasises the need for government and healthcare institutions to build trust that has been eroded through systematic discrimination and racism, culturally insensitive healthcare experiences for these groups, and an under-representation of minoritised groups in vaccine trials (GOV.UK, 2020; Razai et al., 2021).

Covid-19 vaccine hesitancy or refusal may also be, in part, due to the wide circulation of misinformation on social media platforms regarding the safety of and intent behind the vaccines. This includes unfounded claims that the 5G mobile networks are connected to the virus and vaccines, that the pandemic is a conspiracy or man-made bioweapon, and that vaccine trial participants have died due to receiving the vaccine (Geldsetzer, 2020; Megget, 2020; Pennycook et al., 2020). Mistrust deriving from this misinformation is likely to perpetuate paranoia and increase anxiety, therefore resulting in hesitancy around, and avoidance of, vaccination, particularly for those who may already have had concerns and misconceptions regarding the accelerated process through which the vaccines were tested and authorised.

## Theoretical Explanations: Adherence, Psychological Wellbeing and Coping

The evidence discussed thus far highlights how a range of individual differences in circumstances, beliefs, attitudes, demographic and personality characteristics can influence perceptions of and adherence to the public health measures issued to combat covid-19. The literature presented regarding psychological wellbeing demonstrates how the mental health consequences of quarantine, lockdown, physical distancing and shielding also seem to vary depending on a range individual circumstances and characteristics.

Given the gravity of the implications of these findings for the public, and for future infectious disease outbreaks, authors in the field of health and mental health have made efforts to conceptualise health behaviours and coping with the stressful circumstances utilising social psychological models of behaviour.

### *The Health Belief Model*

A number of studies have sought to predict and understand adherence to public health interventions issued during the covid-19 pandemic, some of which apply the Health Belief Model (HBM; Rosenstock, 1974; Tong et al., 2020; Alagili & Bamashmous, 2021; Mirzaei et al., 2021; Bechard et al., 2021), a theoretical framework that has been used extensively to examine and understand health beliefs that can predict and influence health behaviour patterns (Alagili & Bamashmous, 2021; Rosenstock et al., 1988). The HBM proposes that the likelihood of a person adopting a particular health-related behaviour is determined by:

- i) belief there is a personal threat of disease or illness (*perceived susceptibility and perceived severity*) and;

- ii) belief in the accessibility and effectiveness of the health-related behaviour that has been recommended (*perceived barriers and perceived benefits*) (Rosenstock, 1974).

These factors themselves are proposed to be influenced by a range of demographic and psychological characteristics, though motivation to engage in the recommended behaviour can also be directly prompted by a 'cue to action'. In the context of the pandemic, 'cues to action' might include things such as signs instructing the public to wear masks, governmental advice communicated through the media (e.g. 'protect the vulnerable'), and observing close others' adherence to the guidance.

Recent research with samples in Iran, Saudi-Arabia, and Jordan has shown that the HBM perceived barriers, perceived benefits and cues to action reliably predicted adopting covid-19 preventative behaviours (Alagili & Bamashmous, 2021; Mirzaei et al., 2021; Tong et al., 2020). Although the former studies did not find perceived susceptibility or perceived severity predictive of adherence, Tong and their colleagues (2020) found perceived severity of potential infection to be a significant predictor. Similarly, a HBM study with a Canadian sample showed that the perceived benefits of recommended behaviours were the strongest predictors of adherence, with perceived susceptibility and severity indirectly associated through their influence on participants' perceived benefits (Bechard et al., 2021). As discussed, there are also strong findings from other research that voluntary compliance with the covid-19 guidance is significantly predicted by concern for one's own health and belief in effectiveness of the guidance, even when controlling for trust in the government, and sociodemographic and personality characteristics (Clark et al., 2020).

As such, the HBM provides an important theoretical framework to aid our understanding of the variation in adherence behaviours during the covid-19 pandemic and could be key in informing future communication of public health strategies to successfully protect the public and those at increased risk. The HBM can also provide some theoretical insight as to the impact of misinformation on adherence to the covid-19 guidance; mistrust deriving from false information is likely to influence belief in the threat of the virus and effectiveness of the recommended preventative behaviours (i.e. staying home, wearing a mask, shielding, etc.), and therefore the likelihood of adopting them in accordance with the guidance.

### *The Transactional Model of Stress and Coping*

It is well-established that psychological wellbeing has been adversely impacted for many during the covid-19 pandemic. Distress associated with lockdown restrictions has been shown to be particularly elevated in those who report disagreeing with the containment measures (Wissmath et al., 2021), which suggests perceptions of the application of containment measures may, through some mechanism, influence a person's emotional response.

The transactional model of stress and coping (Lazarus & Folkman, 1984) was developed to illustrate the process of coping with situations appraised as stressful. The TSC proposes that our response to a particular event is influenced by the extent to which the event is appraised as challenging or threatening, and by our evaluation of our ability to cope with the experience and mediate our stress. Stress is thought to occur when the perceived demands of a challenging situation exceeds our perceived coping resources, and cognitive appraisals of

situational demands vs coping resources are suggested to play a mediating role in the link between experienced stress and psychological wellbeing.

The theory illustrates that when we encounter a situation we make a 'primary appraisal', determining whether it is either a personally desirable situation or a potentially threatening, harmful, or challenging situation. If the a situation is established as threatening in some way, we make a 'secondary appraisal', by which we evaluate our internal coping resources (e.g. resilience and will power), external coping resources (e.g. friends, family, peers, professionals), and practical resources (e.g. financial stability) to prepare to best manage the situation and change or prevent undesired outcomes. Lazarus (1990) explains that coping has two key functions: to regulate unpleasant emotions (emotion-focussed coping) and to generate cognitions and behaviours to solve the problem causing distress (problem-focussed coping). Further, emotional regulatory coping strategies are proposed to be employed in circumstances perceived as stressful in which there is little or no felt control over the problem or situation. These strategies can be adaptive (e.g. involve acceptance and/or appropriately seeking support), but can also be 'maladaptive' (e.g. catastrophising, ruminating on negative perceptions of stress, avoidance or escape behaviours such as drugs and alcohol). Problem-focussed coping is theorised to be applied where there is felt to be control, or some element of control, over the stressful situation. These strategies are generally considered to be adaptive and can involve learning new skills to manage or change the situation, generating practical solutions, or finding new standards of behaviour, as many have during the pandemic.

Previous research has demonstrated that problem-focussed and adaptive emotion-focussed coping strategies are associated with increased psychological wellbeing, compared with

maladaptive emotion-focussed coping, with which wellbeing is negatively correlated (Miller Smedema et al., 2010; Sagone & Elvira De Caroli, 2014). There have been similar findings in the context of the pandemic (Rogowska et al., 2021; Yan et al., 2021).

This small body of existing covid-19 research applying TSC theory is predominantly focussed on appraisals of coping resources, subsequent coping styles and mental health outcomes, with little focus on the impact of perceptions of the event itself. Nonetheless, the TSC can shed some light on the process through which perceptions of the pandemic restrictions may influence individuals' behavioural and emotional responses. For example, from a TSC perspective, perceptions of the restrictions as protective are likely to give rise to different emotional and behavioural responses compared to threatening perceptions of the restrictions. Based on the existing literature we can theorise that an individual may be more vulnerable to adverse psychological consequences if the restrictive measures are appraised as threatening in some way, control over ones' circumstances is perceived to be lacking, and if coping resources are appraised to be insufficient. In turn, an individual who appraises the restrictions as personally protective despite their challenging nature, perceives some level of control over their personal situation, and believes their coping resources are sufficient to manage the problem or resulting stress, may ultimately experience less psychological adversity in face of the restrictions.

Although both the HBM and TSC provide helpful frameworks for considering the role of personal belief and situational appraisal in behavioural action, emotional response and coping, respectively, there are some important limitations. Neither model explicitly incorporates consideration of the inevitable impact of broader personal, cultural, and societal contexts. As such, both neglect to provide space for the role of, for example, the problematic



societal perceptions and systemic oppression often experienced by individuals most socio-economically vulnerable and marginalised. As discussed in this review, these factors are highly relevant to the experiences of those impacted by the public health interventions issues during the pandemic and should be acknowledged and considered in the process of understanding belief, health-behavioural action and situational appraisal.

Nonetheless, consideration of these social psychological models is important for the context of the empirical work in Part Two, which explores how certain perceptions of the intermittent application and withdrawal of shielding restrictions and accompanying practical support may contribute to the psychological wellbeing of and coping strategies employed by individuals classed as high risk.

### **Coercion and Autonomous Choice**

The intermittent restrictions posed limits to individual liberties, and as such, some deem the way in which they were imposed as coercive (Atlani-Duault et al., 2020; Eyawo et al., 2021; Fischer et al., 2020; Kavanagh & Singh, 2020).

Coercion is defined as *'the practice of persuading someone to do something by using force or threats'* (The Oxford Learner's Dictionary, 2022), and is generally conceptualised to obstruct autonomous choice (Pugh, 2020). As previously outlined, over the centuries restrictive public health measures have frequently been imposed accompanied by the moral justification of preventing harm to others and often by legal sanctions for non-adherence. For many this may yield some level of perceived 'threat', whether to ones' own sense of self as a moral agent, or by explicit threat of punishment. The UK covid-19 lockdown restrictions, although initially framed as 'doing our bit' for the collective good, were eventually enforced via threats of fixed penalty fines. Importantly, the additional measures for those advised to shield were

instead framed as advice for ones' own safety, although high risk groups were also legally obligated to abide by the wider restrictions.

Beauchamp & Childress' (2013) theory of autonomy proposes three necessary conditions for autonomous choice with respect to a particular action or decision:

- i) Intentionality: a deliberate, non-accidental action;
- ii) Understanding: an agent must sufficiently comprehend the relevant information in order to make a decision;
- iii) Non-control: There must be absence of internal or external controlling influences that determine the action. Internal controls include mental health impacts that can interfere with the decision making process, or states such as addiction. External controls include *undue* influence from another person, such as deception or coercion.

Conceptually, then, the imposition of restrictive public health measures such as lockdown potentially limits autonomous choice particularly by obstructing the third condition – non-control – *if* an agent perceives the measures and accompanying endorsements as unwarranted.

Although the UK public were regularly updated with national statistics to illuminate the rationale for the level of restriction at a given time, the public were afforded little influence or control over the intermittent restrictions themselves. It has been established that adherence was variable, though that most agreed the restrictions were justified and were willing to comply (Jeffrey et al., 2020). The majority of the general public also celebrated the exiting of lockdown during periods in which restrictions were relaxed. However, it is rarely considered how the intermittent nature of the restrictions, shielding guidance, and

intermittent withdrawal of support to stay home, impacted those classed as high risk, many of whom were expected to return to work and resume 'life as normal' despite the remaining threat of the virus. We must therefore also consider how these expectations to return to 'normality' could serve to obstruct the third condition of autonomous choice for those in high risk groups.

Accordingly, practices that inflict limits on individual freedom and autonomy have strong potential to give rise to perceptions of coercion in those affected, which has been linked to psychological wellbeing in previous studies involving psychiatric populations.

### *'Perceived Coercion'*

Perceptions of coercion are most commonly reported by individuals who have experienced a situation that is felt to have been forced onto them without sufficient justification, and where they have felt to have had a lack of control, choice or influence during the respective decision-making process (Lidz et al., 1998). Many individuals involuntarily admitted to psychiatric hospital under the Mental Health Act (MHA; 1983) acknowledge the coercive nature of hospital treatment (Burns et al., 2016). Whilst some legally detained patients have reflected a view that use of coercion can be necessary to ensure beneficial treatment to restore judgement is administered, others report experiencing their hospitalisation as an unjust violation of their autonomy and believe their difficulties could have been better managed using less coercive interventions (Katsakou et al., 2012).

It is generally assumed that, on the contrary, patients who are treated on a legally voluntary basis willingly participate in their psychiatric care and do not feel pressured to comply with

their hospital treatment (Katsakou et al., 2011). However, research indicates that between 10% to 50% of legally voluntary psychiatric patients have felt excluded from treatment-related decisions and psychologically coerced into informal hospitalisations through persuasion, pressure, and threats from professionals or their families (Rogers, 1993; Monahan et al., 1995; Hiday et al., 1997; Kjellin et al., 2004). In fact, informal coercion in the form of constant supervision and threat-like ultimatums can be perceived as worse than formal coercion under the MHA (Gerle et al., 2019); it must be noted that this is considered poor practice.

In the psychiatric literature, perceived coercion is traditionally measured using the MacArthur Admission Experience Survey (Gardner et al., 1993), comprised of three subscales derived from interviews with participants with lived experience of voluntary psychiatric hospitalisation. The first measures 'perceived coercion' and is composed of questionnaire items related to perceptions of influence, control, choice, freedom and idea. The second measures 'negative pressures', which relates to perceptions of the process of hospitalisation itself and whether threats or force were involved. The third scale measures 'voice', and is composed of items focussing on the extent to which individuals experienced a space to express their viewpoints and opinions and feel heard by treatment decision-makers.

Higher levels of perceived coercion in informally admitted populations has been shown to be predictive of a poorer prognosis, and can have lasting psychological effects after hospital treatment that can adversely impact future service engagement (Priebe et al., 2011; Gerle et al., 2019). Factors such as poor satisfaction with treatment, viewing admission as ineffective, not feeling respected by staff, and feeling excluded from admission or treatment decisions, have all been shown to contribute significantly to perceptions of coercion in this population

(Katsakou et al., 2011; Sampogna et al., 2019). However, these perceptions can fluctuate at different timepoints during and following treatment, depending on changes in treatment satisfaction, felt inclusion in care-planning, and relationships with care staff.

Although psychiatric hospitalisation and restrictive measures such as lockdown are different practices, both processes restrict personal freedom and autonomy but are considered justifiable on a temporary basis for ensuring personal and public health and safety. The covid-19 restrictions therefore have potential to give rise to perceptions of coercion, and this is likely to have important implications for the psychological wellbeing of those affected. The COVID-19 Wellbeing Study (Ranieri et al., 2021) is the first to explore perceptions of coercion in the context of the pandemic.

### **The COVID-19 Wellbeing Study**

During the early stages of the pandemic a team of researchers at UCL launched The COVID-19 Wellbeing Study (Ranieri et al., 2021) with a view to examine how perceptions of coercion relating to the lockdown restrictions may impact on psychological wellbeing, coping, and post-traumatic growth in the general public and frontline healthcare workers across the UK, Ireland, and Norway. Their preliminary findings indicate that a number of individuals affected by lockdown reported high levels of perceived coercion with regards to these restrictive measures, with higher levels of perceived coercion associated with increased levels of distress (Ranieri *et al*, 2022, unpublished).

The qualitative work presented in Part Two was designed as part of the COVID-19 Wellbeing Study, and explores perceptions of coercion and psychological wellbeing in high risk groups intermittently advised to shield during the pandemic.

### **Research Aims**

Although there is a small body of research exploring the mental health of individuals advised to shield, there is still much to be learned about the psychological impact of the UK covid-19 shielding policy and its' intermittent nature for high risk groups. This is an important area to investigate that could meaningfully contribute to the body of literature that may inform public health responses to future serious infectious disease outbreaks and strategies to protect individuals at increased clinical risk.

The qualitative study described in Part Two is exploratory, and seeks to investigate how individuals classed as high risk experienced receiving instructions to shield, the process of shielding itself, and the expectations to stop shielding at various stages during the pandemic. How these experiences may have impacted on these individuals' perceptions of coercion and on their psychological wellbeing will also be explored, with an additional focus on the ways in which these individuals cared for their own emotional wellbeing throughout the pandemic.

Themes identified in the qualitative data with regards to experiences of the intermittent shielding advice, including perceptions of coercion, psychological wellbeing and coping, will be explored in the context of the literature and theoretical frameworks discussed in this review.

### **Conclusions**

The covid-19 pandemic poses a significant global public health challenge resulting in many countries applying restrictive and preventative measures such as lockdowns and shielding policies in order to curb the spread of the disease and protect those at increased vulnerability of adverse consequences. The measures inherently restrict individual liberties, and although necessary for minimising mortality, have had a significant impact on the wellbeing of the public, many of whom have experienced dire mental health, social, and financial consequences. Emerging findings suggest that individuals classed as high risk and instructed to shield have also suffered some adverse psychological consequences. The majority of the population have willingly abided by the restrictions, though some have deemed the way in which they were instigated and enforced as coercive and threatening to personal freedom and autonomy. As such, adherence to the restrictions has been far from universal, and research has indicated a number of factors associated with the public variability in adherence.

Practices that restrict individual liberties have been associated with perceptions of coercion and related adverse psychological outcomes in psychiatric populations. Preliminary findings from The Covid-19 Wellbeing study indicate that higher levels of perceived coercion associated with the pandemic restrictions is predictive of increased levels of distress. The potential for perceived coercion to arise in situations where safety structures are removed, such as the ending of shielding support and advice to return to 'life as normal', has not yet been examined. Research exploring the experiences and perceptions of people classed as high risk and advised to shield intermittently is required to inform future public health strategies for protecting both the physical and mental health of these groups, both in the short- and long-term. One such study investigating perceptions of coercion and psychological wellbeing of high risk individuals during the pandemic is reported in Part Two.

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## **Part Two: Empirical Paper**

The COVID-19 Wellbeing Study: Psychological wellbeing and perceptions of coercion amongst individuals intermittently advised to shield during the COVID-19 pandemic

## Abstract

*Background:* During the covid-19 pandemic many countries applied restrictive measures such as lockdowns to curb the spread of disease. High risk groups were advised to 'shield' intermittently. Research concerning previous epidemics indicates restrictive measures can impact psychological wellbeing. Practices that restrict freedom have been associated with perceptions of coercion and adverse psychological outcomes in psychiatric populations. The potential for perceived coercion to arise where safety structures are removed has not yet been explored.

*Aims:* The present study forms a qualitative part of the wider COVID-19 Wellbeing Study (Ranieri *et al*, 2020) and aims to better understand the lived experiences of individuals considered high risk who have been intermittently advised to shield throughout the pandemic, and to explore how these experiences relate to perceptions of coercion and psychological wellbeing.

*Method:* Twenty-four participants were recruited from a sample of those who previously completed the wider research study survey. Three online asynchronous virtual focus groups were each held over a period of three weeks between May-June 2021. Transcripts are analysed using thematic analysis to identify themes and describe patterns between responses with a commitment to a phenomenological approach to interpretation and coding.

*Results:* Themes identified were organised into seven domains relating to commitment to health-related behaviours, reintegration, experiences and perceptions of shielding, managing challenges, the high risk status, behaviours of others, and government management.

*Conclusions:* The findings contribute importantly to literature surrounding the pandemic and are discussed in the context of existing theoretical frameworks with regards to beliefs, behaviours, and perceived coercion.



## Introduction

The covid-19 pandemic has brought forth a significant worldwide public health threat prompting many countries to apply restrictive measures with a view to curb the spread of the disease and minimise harm to the public, including lockdowns, physical distancing, and non-essential travel restrictions. During March 2020 approximately 2.2 million UK residents were identified to be at an increased vulnerability to covid-19 (Office for National Statistics, 2020) due to underlying health conditions, such as diabetes or specific forms of cancer, and were advised to take additionally stringent precautions for their own safety. This was termed 'shielding'; those classified as high risk received official medical advice to stay home at all times, avoid all non-essential contacts, and to spend minimal time in communal areas in shared households. In February 2021, the high risk classification was extended to include another 1.7 million UK residents based on covid-19 risk modelling which incorporated additional risk factors such as age, ethnicity, BMI, socioeconomic deprivation, ongoing treatment, and other specific health conditions (Clift et al., 2020). Recipients of official shielding advice were afforded access to practical support structures to enable their safely staying at home, including priority grocery delivery slots, government food parcels, prescription delivery, and government approval to stay home from work on medical grounds.

Restrictive public health measures such as quarantines have long been adopted by government authorities in the context of serious infectious disease outbreaks, and can be highly beneficial in minimising disease spread where there is limited access to effective medical treatment (Tognotti, 2013). However, due to the limits these practices place on individual liberties such as freedom of movement and autonomy, these strategies have been criticised by many who perceive their application as intrusive and coercive (Atlani-Duault et

al., 2020; Cetron & Landwirth, 2005). As such, the pandemic was accompanied by heightened social and political tensions, with social inequalities becoming further intensified across the globe (Gerbaudo, 2020). Anti-lockdown protests were instigated by a number of civilians across several countries, including the UK, who viewed the public health restrictions as breaching civil rights (Aaron, 2020; Chaudhary & Kumar, 2020). Furthermore, although data indicates the majority of UK citizens complied with restrictions and were accepting of their justification to prevent harm and protect the NHS from becoming overwhelmed, evidence also shows that the extent of adherence to rules and recommendations varied (Adam, 2020; Gunia, 2020). Research indicates extent of adherence was associated with a wide variety of individual, social and environmental factors, such as political ideological extremity, trust in government, and warmer temperatures (Brouard et al., 2020; Bargain & Aminjonov, 2020; Ganslmeier et al., 2022).

A wide body of research continues to emerge demonstrating the impact of covid-19 restrictions on psychological wellbeing. Many citizens reported a significant increase in loneliness as a result of the pandemic (Buecker & Horstmann, 2021), which was shown to be positively associated with adverse mental health outcomes (for a review, see Pai & Vella, 2021). Research demonstrates the pandemic was accompanied by increased psychological distress and symptoms of depression, anxiety and PTSD, and exacerbated many additional risk factors including financial insecurity and suicidal isolation (Pierce et al., 2020; O'Connor et al., 2021; Cénat et al., 2021; Chekole & Abate, 2021). Individuals from minoritised groups and lower socioeconomic backgrounds were demonstrated to be disproportionately impacted by the restrictions with regards to these mental health consequences (Mattos dos Santos, 2020; Proto & Quintana-Domeque, 2021).

A small body of literature explores the psychological experiences of the pandemic for individuals who shielded, advised to abide by guidance more restrictive than that legislated for the rest of the public. There was increased anxiety reported among shielding groups in relation to the virus given the life-threatening risks it posed to these individuals, and great support for the shielding policy and the protection it enabled (Sloan et al., 2021). However, many reported a significant impact of isolation itself on their quality of life and mental health, including increased loneliness, depression and anxiety, and for some the high risk classification came with a perceived negative impact on social identity, although coupled with a sense of validation for the seriousness of their risk (Gessa & Price, 2021; Lasseter et al., 2022; Sloan et al., 2021; Webb, 2021). Research conducted during official shielding periods also highlighted particular concern and uncertainty relating to the eventual lifting of shielding and return to work (Harris et al., 2020; Sloan et al., 2021)

Existing theoretical frameworks have been applied to understand adherence to health-related behavioural recommendations and to shed light on experiences of distress and coping during the covid-19 pandemic. The Health Belief Model (HBM; Rosenstock, 1974) is one such framework used to examine health beliefs and behaviours, and posits that likelihood of adopting a health-related behaviour is determined by beliefs surrounding the perceived threat of a disease and belief in the effectiveness and accessibility of the recommended behaviour. Research indicates that the perceived benefits of covid-19 behaviour recommendations and concern for ones' own health was predictive of adherence to restrictions and recommendations (Bechard et al., 2021; Clark et al., 2020).

The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) is useful for illustrating the process through which appraisals of an event and evaluation of ones' own

coping resources can mediate felt distress. Increased distress is proposed to occur when an event appraised as challenging or threatening is evaluated to exceed available coping resources. Accordingly, lockdown-related distress was particularly heightened for those who disagreed with the measures (Wissmath et al., 2021). The limited covid-19 research applying this framework highlights the effectiveness of different coping styles and resources for managing psychological wellbeing, with adaptive problem- and emotion-focussed coping strategies associated with better psychological wellbeing compared with maladaptive strategies, such as drug use (Rogowska et al., 2021; Yan et al., 2021). However, covid-19 studies applying this model neglect to examine the nature and impact of specific appraisals relating to the restrictions.

The measures applied during the covid-19 pandemic are largely considered sufficiently ethically and legally justifiable by John Stuart Mill's 'harm principle': to mitigate harm from infected persons to others (Matose & Lanphier, 2020; Mill, 2003). However, practices which restrict individual liberties by placing limits on personal freedom and autonomy have potential to produce perceptions of coercion (Gerbaudo, 2020; Tognotti, 2013), which has been associated with psychological wellbeing in research involving psychiatric populations.

The psychiatric literature highlights that up to 50% of psychiatric patients who are not legally detained but rather voluntarily admitted have reported feeling excluded from decisions surrounding their treatment and psychologically coerced into informal admission through pressure and perceived threats from professionals or family (Hiday et al., 1997; Kjellin et al., 2004; Monahan et al., 1995; Rogers, 1993). Higher rates of perceived coercion can have lasting adverse psychological effects, impact future service engagement, and predict a poorer mental health prognosis (Gerle et al., 2019; Priebe et al., 2011). Perceptions of coercion in

this context can fluctuate, and are contributed to by a number of factors including poor treatment satisfaction, viewing treatment as ineffective and exclusion from treatment decisions (Katsakou et al., 2011; Sampogna et al., 2019).

‘Perceived coercion’ as a measurable construct in the psychiatric literature is based on: i) the perceived extent of personal freedom, choice, control, and influence over treatment decisions; ii) perceptions of having been forced or threatened to comply with decisions; and iii) the extent to which one has felt to have a voice in the decision process affecting them (Gardner et al., 1993; Golay et al., 2017). Perceptions of ‘procedural justice’ relating to the fairness and transparency of the process through which treatment decisions have been applied is also closely linked to perceived coercion (Simpson et al., 2020). During the pandemic the public had no agency in influencing decisions surrounding the restrictions, and as such, there are bound to be parallels to the factors described above experienced by those affected by the decisions made by authorities during the covid-19 pandemic.

To the researchers’ knowledge the Covid-19 Wellbeing Study (Ranieri et al., 2021) is the first project to explore perceptions of coercion in the context of the restrictive measures imposed during the pandemic. This offers an important contribution to the pandemic literature and may shed new light on the impact of restrictions on the public’s psychological wellbeing. The potential for the withdrawal of restrictive measures to give rise to perceptions of coercion where the restrictions have mitigated personal risk has not yet been explored.

The present study forms a qualitative extension to the Covid-19 Wellbeing Study and seeks to explore the experiences of individuals classed as high risk and intermittently advised to shield, with a specific focus on how these experiences shaped their perceptions of coercion and impacted their psychological wellbeing. The research questions of interest are influenced

primarily by the theory behind the theoretical frameworks chronicled above (namely, the HBM, TSC, and literature surrounding perceived coercion), and seek to hold in mind the potential influence of health beliefs, perceptions of personal risk, and appraisals of the UK's particular public health approaches to managing the covid-19 pandemic with regards to the way in which shielding advice and shielding itself was perceived, adopted, and experienced. Findings will be explored and discussed in relation to the literature and to these theoretical frameworks.

Accordingly, this study seeks to explore the following research questions:

1. How have individuals who have been classed as 'high risk' experienced receiving intermittent advice to shield and shielding itself during the COVID-19 pandemic?
2. How have these experiences impacted on these individuals' perceptions of coercion and psychological wellbeing?
3. How have these individuals experienced the intermittent lifting of official shielding guidance?
4. How have experiences of the shielding guidance being lifted impacted on perceptions of coercion and psychological wellbeing?
5. How have these individuals cared for their own psychological wellbeing during the COVID-19 pandemic?

## **Methods**

### *Design*

This study comprises a qualitative part of a wider Covid-19 Wellbeing Study (for the protocol, see Ranieri et al., 2021), which applies a mixed-methods approach to examining the impact of the covid-19 restrictions on perceptions of coercion, psychological wellbeing and coping amongst citizens of the UK, Ireland, and Norway.

The present study employed a qualitative design to explore the subjective experiences of people classed as high risk and intermittently advised to shield during the covid-19 pandemic.

### *Ethical Approval*

This project received approval by the Research Ethics Committee at University College London following specific amendments to the wider study ethics application (see Appendices A and B).

### *Participants*

Twenty-four participants residing in the UK who had previously taken part in the wider study survey were purposively selected and recruited via email, having consented to further contact. Recruitment for the wider study took place through social media platforms (e.g. Facebook and Instagram). Only participants who confirmed during screening for this study that they had received official advice to shield during the pandemic were included in the present study. Where possible, participants invited were purposively selected according to their age, gender, ethnicity, and geographical location.

It was noted that respondents from the wider study were predominantly white and female. With a view to maximise diversity of the sample given the literature surrounding the disproportionate impact of the pandemic on ethnically minoritised groups, efforts were made to extend recruitment by posting adverts on Facebook groups formed by and for people from

Black, Asian and minoritised ethnic backgrounds who had been advised to shield. However, this process did not yield further participants.

Participant demographic information was taken from the wider research study data. Note that this did not include participants' particular level of risk or health condition, only whether they had been classified as high risk. Twenty participants were living across England (83.3%), with two residing in Scotland (8.3%) and two in Wales (8.3%; see Appendix C for regional breakdown). All participants who responded to the invitation described themselves as ethnically White. Twenty participants identified as female and three identified as male. Ages ranged from 32 to 76 years ( $M = 56.79$ ,  $SD = 11.74$ ; see Appendix D).

Twenty-five participants were originally recruited and provided consent, however, one did not post any responses in their focus group and therefore their data has been excluded.

The 24 participants were divided into three focus groups (Group 1:  $n = 9$ ; Group 2:  $n = 6$ ; Group 3:  $n = 9$ ) based on the round of email invitations responded to.

### *Procedures*

The present study employed Asynchronous Virtual Focus Groups (AVFGs). AVFGs are similar to traditional focus groups, but are held online typically over an extended period of several weeks (Ranieri et al., 2019; Williams et al., 2012). They provide the opportunity for participants to type responses to questions and interact with each other's responses. This method has been applied effectively with diverse and vulnerable populations (Ranieri et al., 2019, 2020; Zwaanswijk & van Dulmen, 2014) and provides valuable advantages in the context of shielding guidelines as participants can anonymously take part at any time of their choosing from the comfort of their own homes. The AVFGs were hosted on UCL EXTend, a



virtual learning environment that provides a data-secure and confidential forum for participants to anonymously engage.

Participants were invited via email to participate in AVFGs and asked to confirm they received official shielding advice. They were asked to select an anonymous 'alias' for use in the AVFGs in order to protect personal data and maintain confidentiality within the forum. Participants generally used celebrity names, the names of fictional characters, or an unidentifiable nickname. Via email, participants received their anonymous UCL EXTend username and password with which to log into the platform, along with a document containing detailed instructions on how to navigate the platform (see Appendix E). Prior to commencing the AVFGs, participants were required to read a study information sheet (see Appendix F). In order to enable their access to the discussion forum, participants were required to read the consent form (see Appendix G) and provide their informed consent within a mandatory module on UCL EXTend (for consent records see Appendix H). Participants were then directed to a document detailing ground-rules for interactions within the AVFGs (see Appendix I) and provided with key contact details for use in the event of becoming distressed or displeased with the participation process (Appendix J).

The AVFG questions were composed collaboratively with researchers involved in the wider Covid-19 Wellbeing Study, informed by the data emerging and by the theory behind the HBM, TSC, and literature surrounding perceived coercion. These models informed the language used (e.g., 'safe to stop shielding', 'choice', 'control') and the particular questions asked with an aim to illuminate participants' experiences in the context of their personal beliefs and appraisals surrounding their risk classification and intermittent shielding advice. Additional consultation was provided by five individuals residing in the UK who had been classed as high risk and

advised to shield during the pandemic. They were approached through the researcher’s social networks. The questions are displayed in Table 1.

**Table 1.**

*Asynchronous Virtual Focus Group topics and questions presented according to week*

<b>Week</b>	<b>Topic/Questions</b>
Week One	<p><i>Introductory Questions:</i></p> <p>What have you understood about the requirements of shielding during the pandemic for those who are extremely clinically vulnerable? What was it like receiving a letter advising you to shield because you are considered extremely clinically vulnerable?</p> <p><i>Experiences of shielding and perceptions of coercion.</i> From our survey, some individuals reported feeling coerced as they experienced a loss of choice, control and freedom over their lives due to government-imposed restrictions.</p> <p>Reflecting on your own personal circumstances, what has shielding been like for you? Did you feel you had choice/control over your shielding? Has the instruction to shield felt reasonable/justified? Were there any times you felt pressured to relax your shielding despite the instructions?</p>
Week Two	<p><i>Experiences of shielding advice being paused</i> At various points during the pandemic advice to shield has been paused and restrictions have been eased, with the most recent period of shielding instructions having ended on 1<sup>st</sup> April.</p> <p>Can you tell us what was this has been/is like for you? Have you felt safe to stop shielding? Have you felt you have had choice or control over whether you stop shielding? What sorts of activities have you felt free to do when not technically shielding?</p>
Week Three	<p><i>Psychological Wellbeing</i></p> <p>How have the restrictions associated with shielding and the wider restrictions (e.g. tier Systems/national lockdowns) impacted on your psychological wellbeing? Is there anything you have found to be helpful for your psychological wellbeing whilst you have been shielding (e.g. coping strategies, activities)? What has made you feel supported or unsupported? What support do you feel you would benefit from if this were to happen again in the future?</p> <p><i>Final thoughts and reflections</i> What has it been like hearing about each other’s experiences?</p>

A total of three AVFGs were conducted simultaneously, each lasting three weeks, staggered to begin one week after the other. The data collection took place over a total period of five weeks between May and June 2021. Note that at this time, official shielding advice had been lifted from April 1<sup>st</sup> 2021. During the AVFGs participants were asked to engage with and respond to a number of questions. Participants were encouraged to engage with each other’s responses. Each week the researcher posted new questions. The AVFG forum was reviewed and

moderated at least twice daily, and additional prompts and follow-up questions were posted by the researcher depending on the level of group activity and engagement.

### *Analysis*

Descriptive statistics with regards to participant demographics were calculated using IBM SPSS Statistics for Windows software.

*This study adopted a phenomenological approach with a view to gain understanding of participants' subjective lived experiences and the meanings ascribed to them (Giorgi, 2012). AVFG data scripts were extracted directly as text from UCL EXtend and analysed using thematic analysis (Braun & Clarke, 2006), supported by NVivo 12 software for Windows. Braun & Clarke (2006) specify six distinct methodological phases involved in high quality thematic analysis. As such, the analysis was an organic process involving repeated reading of transcripts for familiarisation, generating initial codes, searching for themes within the coded data, reviewing themes to verify the accuracy of the data categorisation, and defining themes and sub-themes. Themes were further refined across domains during the reporting phase. Initial codes and themes were identified through an inductive approach and at a semantic level, derived from the explicit surface level meanings of the data. The analysis involved a progression from organisation of descriptions representing patterns in semantic content, to interpretation of the patterns in relation to previous literature and existing theoretical frameworks. An example extract illustrating initial semantic-level coding and a representation of the thematic categorisation phase are presented in Appendix K and L, respectively. Participants' language was assumed to reflect real world constructs and the analysis aimed both to describe and interpret the meanings embedded throughout the data. Data was analysed across and within the three focus groups.*

*Researcher Perspective*

Contextualising the researcher through perspective disclosure is considered to valuably contribute to the validity of qualitative research for readers (Caelli et al., 2003) and is particularly important to consider when conducting outsider research (Dwyer & Buckle, 2009). The researcher is an able-bodied, middle-class, white-Hispanic British woman in her late 20s, and this research is being conducted as part of a doctorate in Clinical Psychology.

The researcher experienced covid-19 restrictions in the UK, though was not classified as high risk or advised to shield. The researcher was motivated to conduct this research having noticed a lack of media representation of the voices of those who had been classed as clinically extremely vulnerable to covid-19 and advised to isolate more stringently than the rest of the public in the interest of protecting their own lives. Having worked within psychiatric inpatient contexts, the concept of perceived coercion is of great importance to the researcher, and with the intermittent nature of the shielding advice and support this presented a unique opportunity to explore this concept through a novel lens.

### *Rigour and Reflexivity*

In order to support rigour and reflexivity in the research process, the researcher took opportunities for bracketing during meetings with their research supervisor where existing preconceptions, biases and expectations with regards to the data collection and potential findings were further illuminated. Although this was an informal bracketing process embedded in ordinary discourse surrounding the importance of the research topic, the design, and personal experiences of the pandemic and restrictions, the researcher maintained a reflective log to monitor preconceptions and biases in order to remain committed to the phenomenological approach to data collection, interpretation and analysis of participants' responses. The researcher also provided samples of coding and themes identified to their supervisor for examination at various points during the analysis to support credibility. This included co-consideration of the language used to name the themes identified to ensure a most accurate representation of the participants' lived experiences.

## **Results**

Themes identified were organised into seven domains and are presented below in order of their prominence throughout the data. A thematic map illustrating the position of centrality of identified themes and strong conceptual the links between domains, key themes, and subordinate themes is represented in Appendix M.

Overall, participants were highly engaged and thoroughly interactive with the researcher's questions and with one another's responses during the AVFGs, although some were more active in the groups than others. There was seen to be more between-participant interaction across groups 1 and 2 compared with group 3. Responses in group 3 were seen to be, at points, shorter and more direct in their answering of the researcher's questions in comparison to groups 1 and 2, in which participants generally provided longer responses and shared more about their personal contexts and the ways in which this was felt to link to their experiences.

## Domain 1. **Commitment to health-related behaviours**

### *'Unofficial' Shielding*

Many participants had recognised their clinical risk in the early stages of the pandemic and began effectively shielding before official advice, forming their 'own rules' to stay safe. When shielding was lifted, many understood there to be no change in the risk and felt it was too unsafe to stop shielding; several continued.

*"...I have made my own rules and they have been earlier and more draconian than the government's". – S, age 62*

*"...we did not risk stopping shielding, everything we wanted we ordered online, even though we were told it was safe, we did not feel safe..." – S.H, age 65*

### ***Preserving personal safety***

Most participants felt they could decide the extent to which they followed shielding guidance and in *how* they relaxed their shielding behaviours. The majority made considered efforts to maintain some behaviours associated with shielding after the restrictions and official shielding advice had been lifted to preserve their safety. Many described taking no ‘unnecessary risks’, with some expressing an aim to balance their safety with their need for autonomy and quality of life by re-engaging with a limited range of activities. Whilst not ‘officially’ shielding, many began grocery shopping where they had assessed it as being safest, and socialising only outdoors, physically distanced. For some, this was paired with only mixing with those vaccinated. A number of participants’ decisions were informed by the number of local covid-19 cases, showing a good understanding of risk. Many shared a sense of hope and expectation that they would feel increasingly comfortable to incrementally drop these health-related behaviours in time.

*“Even though I have had both <vaccinations>, I still keep myself to myself, I do not take unnecessary risks...” S.H, age 65*

*“I need to balance the risk of catching it in an area that has rising cases to my mental health and also not ending up being someone who can't leave the house or never socialise again.” – J.M, age 39*

### ***Personal circumstances***

Decisions regarding the extent of commitment to health-related behaviours were felt by some to be dependent on their specific circumstances. Some acknowledged that had they not had gardens, been retired, or financially stable enough to resign or to afford equipment to enable home working, their ability to stay safe and cope may have been compromised. A small minority expressed difficulty strictly shielding due to living with others who continued leaving the house, and found this took away some of their control in staying safe.

*“Because I was retired, live alone, but was still able to live independently, I was able to isolate completely”. – S, age 62*

*“I only have a choice because I am nearly retirement age so I can make my own choices but if I had of kept working I would have had no choices and had to work in an environment that I wouldn't have felt safe or protected from the virus.” – B.S, age 61*

## Domain 2. Physical reintegration

### *Readiness for normality*

Where official shielding was lifted, most participants described still feeling very unsafe and worried about returning to ‘normality’. Some continued to strictly shield, and others made gradual moves towards reintegrating, some doing so solely to meet work expectations, others to balance their need for safety with a longing for life as it was. Many expressed having experienced the end of official shielding as sudden, with a lack of scaffolding provided for their safe return to normality.

*“When shielding was stopped; I feel like we were just dropped into ‘normality’ like nothing had happened and it messed with a lot of people’s minds, and caused a lot of anxiety.” –*

*A.X, age 40*

*“Now everything is opening up I feel more anxious about venturing out but that is getting better the more I do it .. though I won’t go anywhere indoors yet.” – H.L, age 65*

*“...my daughter had to give me a lot of encouragement to go out. We started with baby steps, just going out for a drive.” – D.I, age 60*

### ***Employment Pressure***

Most experienced distress in relation to pressure from employers to return to work when shielding was lifted, though a small minority felt their employers made efforts to support their continued protection. Some continued home-working. For most, their anticipated and actual transition back to work caused significant stress and anxiety as many reported their workplaces were not covid-secure. Many felt no choice about their return and no control over their safety at work. Some were signed off for stress for short periods or instructed to take annual leave; this contributed to felt stigma and discrimination. Some felt they had no choice but to resign or retire early, and although this felt relieving due to the safety it enabled, participants also shared feelings of disappointment and grief.

*“I felt I had no control and was a battle to get my <occupational health> referral. I originally got ‘the government say it's safe to return so you can’. What I actually felt was,*



*they just cut us off, with no help, advice or anything and as numbers were still high.” –*

J.M, age 39

*“I had to give up my job as I felt it was unsafe for me to return.” – M.T, age 65*

*“I handed in my notice when I was called back after the 2nd lockdown... I couldn't deal with going back into battle with my employer, so I threw in the towel. It was a very difficult decision to take and it caused me a lot of soul searching and sadness. I loved my job...” – D.I, age 60*

### ***Vaccination and immunity***

There were mixed experiences around the sense of safety provided by vaccination, although it was evident those who discussed vaccinations had been pleased to receive them. Some felt they were safer to relax some of their shielding behaviours knowing others had been vaccinated too, although several also expressed continued concern due to news of new variants and uncertainty as to the protection against them. There was concern for some participants about their extent of immunity, with some sharing they had ordered antibody tests to ensure their reintegration behaviours were well-informed. There were some who continued to feel too unsafe to leave their homes despite vaccination in case they had not developed sufficient immunity.

*“For me, the latest advice about not having to shield has felt more reassuring because I’ve had two vaccines, my husband and youngest son have had 1 vaccine each, so I definitely feel safer.” – M, age 53*

*“...I was told by the doctor who gave me my vaccine that I need to behave as though I’ve not been vaccinated because he’s not sure whether I’ll have an immune response.” – A.X, age 40*

### Domain 3. Perceptions and Experiences of Shielding

#### *Positive experiences and perceptions*

Most highly supported the shielding policy and wider restrictions and believed these measures were justified by the risks they mitigated. Many felt it was their decision to shield and were reassured in knowing it was not enforceable, however, a small minority felt they had no choice but to shield for survival. Participants valued the control they had over their safety at home. Some initially found it a manageable adjustment, particularly participants who had adjusted to staying home pre-pandemic due to their health conditions. Most experienced shielding as protective despite the challenges and many appreciated some pleasantries of being at home, spending time with family and taking time to oneself to reflect without pressure to go out.

*“The first period of shielding in March 2020; was actually a really positive experience for me. I was relieved to be at home and safe. My mantra was ‘you’re not stuck at home, you’re safe at home’. I had time to rediscover myself and just some ‘me’ time.” – A.X, age 40*

*“I felt I had no choice over the shielding issue.. I would have been stupid not too and I felt it was justified given my health problems.” – H.L, age 65*

*“We became a fortress, an impregnable bubble where we got everything delivered to our door, with no need to go out into the plague ridden world. We knew we could not allow anyone in, and we weren't going out anytime soon.” – S.C, age 59*

### ***Psychological challenges of shielding***

*Isolation, Loneliness, and Loss.* Many expressed a sense of loneliness and loss in the context of isolation. Many participants described feeling highly emotionally impacted by the loss of closeness and hugs with friends and family, particularly where participants did not live near their loved ones. There was also a heavy sense of loss described by some in relation to being unable to participate in activities and hobbies once enjoyed. For some, this extended isolation was accompanied by a sense of losing the ability and skills to socialise. These experiences were most discussed across groups 1 and 2.

*“The hardest part was not being able to see my family and Grandchildren.” – S.D, age 69*

*“I worry now whether I will regain my ability to socialise in the same way with friends”. -  
N.D, age 76*

*“The loneliness and isolation just make you go in on yourself and often people you know don't realise so just leave you to it as they have their own stuff going on”. – L.P, age 32*

*“I'm a musician. I could no longer play music with anyone... I've been playing music with others since the age of 7. That was such a huge loss...” – S, age 62*

Mood and Mental Health: Many described pronounced changes in their mood and mental health. For many, this included trouble sleeping, loss of motivation, feeling anxious, irritable, angry, and emotionally overwhelmed, with 'small things' leading to heightened emotional responses. One participant felt they had become 'agoraphobic'. There was a widespread sense of feeling trapped embedded in many participants' reflections. It was acknowledged by a small minority who disclosed pre-existing mental health issues that the restrictive nature of shielding served to reinstate behaviours associated with depression and social anxiety, such as withdrawal from the outside world. Some talked of feeling there had been a lack of emotional support for people shielding given the stringency of the advice.

*"As for actually shielding and staying at home, I have social anxiety issues... I had just completed a CBT course which helped me to get more outside... lockdown has set me right back to where I was!" – L.S, age 62*

*"At the start of the pandemic I felt well.... Now I'm on antidepressants following difficulties sleeping and coping with such long term ongoing anxiety." – J, age 62*

*"...my anger through this has definitely raised I was very well known for having a very very very long fuse, now it's just medium length.....I've even had to Google anger management techniques..." – J.M, age 39*

#### Domain 4. Managing the challenges and implications of shielding

## *Access to essentials*

Participants widely expressed worry and concern due to uncertainty around access to food and other essentials in the early stages of the pandemic and particularly before shielding was officially advised. For the majority, reliable and consistent safe access to essentials, whether provided by family, friends, neighbours or supermarket delivery, was felt to be absolutely crucial for participants' felt ability to cope. Although participants expressed feeling supported and protected by the practical support official advice enabled, such as priority delivery slots and food packages, some voiced frustration in being unable to do their own shopping in person. Many described difficulties in practically utilising these help structures due to inadequate stock and delivery substitutions. Some shared they had found this highly emotionally impactful; it seemed to reinforce the felt loss of autonomy that came with their shielding experiences.

*"Yes problems with getting shopping were a main issue for us too. Not getting basics repeatedly ordered would initially reduce me to tears of frustration." J, age 62*

*"I felt very supported through lockdowns and shielding periods- I had a priority Asda delivery slot, kept receiving Boris boxes full of oversized onions, pasta and... had my prescriptions delivered and was offered help from my local council..." – P, age 57*

*"I was really pleased with how my local council stepped up to offer a drop off/ collect library service. The original support of food deliveries from the major supermarkets was a life-saver." – H.L, age 65*

### *Finding ways to cope*

A variety of strategies were applied to manage emotions and cope with shielding, some extensions of pre-existing strategies, others new mechanisms adopted to cope with the novel situation. Many emphasised maintaining structure, setting work/leisure boundaries and keeping themselves busy with new and existing hobbies and enjoyable activities. For some, staying focussed on the positives helped, for others, connecting with their feelings with compassion and self-validation felt most essential. Online events, social media and other communication platforms were highly valued for entertainment, reducing felt isolation and maintaining a sense of connection with loved ones, colleagues, and online communities. Some felt they would not have coped without this, however, embedded in these expressions was also a sense that this world did not fully satisfy the need for human connection.

Time outdoors was highly valued by the majority. Many voiced appreciation for private gardens, which enabled socially distanced visits and fresh air without compromising safety. Some found initial advice not to leave the house even for exercise particularly challenging, and it was suggested by some this should be reconsidered in the future. Most described having gone walking later in the pandemic and found this highly beneficial for their physical and mental wellbeing.

Staying informed regarding covid-19 cases and associated measures was also expressed to be important for managing wellbeing by facilitating a felt control over ones' choices and gaining insight into their future. For some, however, this exacerbated frustration and disagreement with governmental decisions.

*“Mantras, things I say to myself, like 'you're safe', 'you're doing great' 'well done'*

*Going with the flow, being kind to myself, setting my expectations low... Finding activities I liked and could do daily. I like having simple daily goals...” – T.L, age 61*

*“Being able to go outside in a safe place and also being able to see the sky and my neighbour's olive tree has helped.” – S, age 62*

*“The continuation of several things I used to do in person have moved online, this has helped somewhat to remove the isolating feeling”. – Y.D, age 37*

*“I like to keep in touch with what is happening locally as well as nationally so that I can make informed choices.” – N.D, 76*

## **Community**

Camaraderie: Particularly during the first national lockdown, participants felt considerably supported by being ‘all in this together’. Many observed supportive attitudes communicated by local communities, with many people offering practical support to those shielding. This sense of camaraderie, however, was thought to have dwindled as the pandemic went on and the general public were increasingly able to re-engage with their usual lives.

*“...it really felt like we were all in it together. However, the subsequent shielding period/lockdown did not feel the same. I think because it was only a shorter period of time for non-shielding individuals- the ‘in it together’ camaraderie had all but gone... it felt like the public view was; just lock the sick and elderly away and let the rest of the world get on with living.” – A.X, age 40*

*“Someone in my street started a Facebook page for residents and I signed up for this and found it really helpful to be able to be in contact with neighbours via this page and neighbours offered to pick up food etc if I needed them to.” – N.D, age 76*

Relationships: The value of maintaining meaningful relationships was powerfully evident.

Ability to connect through social media was crucial for most, and those who lived with others expressed gratitude for the time they had together. Relationships in which participants felt supported in their decisions regarding commitment to safety-preserving behaviours were highly valued. Some, however, felt judged by friends and family for their choices to keep safe, with relationships strained as a consequence. This coupled with a sense of coming out of the pandemic knowing who truly cares and matters in their lives.

*“I've found out who my real friends are, e.g. the ones who respect my decision to keep away from others and compromise to mean we can still meet up and I feel safe and others who don't give a shit...” – J.M, age 39*

*“Zoom and other platforms - I would have gone mad without this link to people. It has enhanced my life...” – S, age 62*

### **Sharing Stories**

Many were validated through hearing each other's experiences and feelings during the focus groups, with many interacting with others' posts providing solidarity and reassurance that the way they had felt was understandable. It was evident many had felt alone in their shielding,



and some suggested that anonymous support groups for people shielding where stories could be shared may have been valuable for managing this during the pandemic. Embedded in people's reflections was a sense that the voices of people shielding had been left unheard by the rest of the public and the decision-makers.

*"It's been really encouraging to know in not alone in the struggles and impact". – L.P, age 32*

*"It's been good to hear the other peoples thoughts and feelings, and to know that others share your concerns too. It feels like my own anxiety and worries are validated. That I'm not being over cautious; this virus is a real threat to us and one it appears that we've all taken seriously and been keeping ourselves safe." – A.X, age 40*

*"There were (and still are) so many people in Facebook groups who felt that it was impossible to get the, "at the coal face" reality across to the decision makers." – D.I, age 60*

*"By bringing us together nationally and globally, this research project hints at a more powerful way forward for the shielded, an under- and often mis- represented group in our society." – S, age 62*

## Domain 5. UK Government Handling

### *Perceptions of policy decisions and government attitudes*

Although many initially felt protected and held in mind by the government given the safety structures offered, most conveyed striking dissatisfaction with many of the governments' decisions as the pandemic progressed and expressed contempt towards the attitudes believed to be implicit in them. Participants communicated a strong sense of having been forgotten and let down by the government and a perception that pleasing the rest of the public and protecting the economy was prioritised over the livelihoods of those classified as high risk. Many felt the government had acted slowly and carelessly in initiating and re-instating restrictions despite their knowledge of the data regarding the trajectory of covid-19 spread, although a small minority believed they had done the best they could in an unprecedented situation. Some spoke of hearing about covid-19 positive patients being returned to care homes, and expressed believing this reflected a lack of value and care for this population. Some participants experienced a shift in their perception of the intentions behind the shielding policy, and began to feel that shielding had been established only to prevent the NHS becoming overwhelmed, with the lifting of shielding reflecting renewed bed capacity, not a reduced risk.

Some felt fortunate in benefitting from the furlough scheme, although many believed its accessibility for shielding groups was poorly considered, with many 'healthy' individuals claiming furlough whilst several participants were compulsorily signed off on statutory sick pay. Some believed it should have been mandatory for employers to furlough high risk individuals whose jobs were not suitable for home-working.

*“Westminster government's chaotic laissez faire approach, the pm missing COBRA meetings, delaying lockdown, not closing borders, letting planes in from India after we*

*knew about the Indian variant, letting covid positive back into care homes, I'm afraid of the Westminster government.” – T.L, age 61*

*“They acted late, they were chaotic, had no plans, no PPE and couldn't learn from mistakes.” – J, age 62*

*“...they scare the pants off us to make sure we stay away from people so we don't get ill, now it feels like, well we don't care if you get it now there is a hospital bed to treat you, doesn't matter if you get really sick & end up with long covid or worse, dead....” – J.M, age 39*

*“...many shielders were classed as disabled; the fact they were left up to employers discretion whether to furlough or give SSP was wrong. It's like financial punishment for having a disability.” – A.X, age 40*

*“I thought most of the responses have been political (Eat out to help out) rather than medical or science driven. And I ended up trusting the politicians even less.” – L.S, age 62*

### ***Guidance communications***

Although most understood the key elements of the shielding advice, many experienced the rule and guidance communications as untimely, unclear and contradictory. Some people's shielding letters were delayed and many felt the wording reflected poor consideration of the emotional impact on high risk groups. Many found them confusing, and some, frightening.

*“...I found a lot of what was said by the PM and <the health secretary> very contradictory, messages changing and rules becoming laws becoming recommendations...” – L.S, age 62*

*“The letter was long and required re-reading to fully understand the guidelines/advice and I imagine that many people would find the letter somewhat confusing.” – B.S, age 61*

*“I found the wording of the government’s letter on shielding very dramatic and to be honest it terrified me after reading it.” – M, age 53*

## Domain 6. Navigating the choices and perceptions of others

### *Others’ Adherence and Expectations*

Most participants felt demoralised, frustrated and/or worried by others’ poor adherence to rules and guidance. There was a spectrum of observed non-adherence reflected, ranging from failing to socially distance, wear masks, get vaccinated and attempting hugs without permission during less restrictive periods, to active rule breaking and engagement in anti-lockdown protests during tighter restrictions. This seemed to reinforce a sense of being uncared for by society. Some saw the public as complacent, behaving as though the risks had gone during the vaccine rollout. Participants felt safer in spaces where people were seen socially distancing and wearing masks, however, this seemed dependent on the culture of participants’ local communities and was not commonly observed across the groups.

Some participants spoke of feeling pressured by expectations from others to relax their shielding at various points. There was an undertone of guilt reflected in some participants’ descriptions of their need to ‘remain selfish’ to preserve safety in the face of wavering

adherence. Some stated they understood others' need to fully reintegrate, but many felt the need to adapt their behaviour where they felt they could not rely on others' compliance to keep them safe, with some experiencing discomfort in needing to remind visitors to observe social distancing.

*"I watch my neighbours having house parties or minimum a few people call in and go into the house every few days. Then I put the TV on to watch the conference and hear numbers are going back up and that "all" the public are doing so well, when in reality, at least my reality they are not." – J.M, age 39*

*"I'm paying a high price for Covid so no wonder I'm pretty angry with those who cannot understand how to keep themselves and others safe". – J, age 62*

*"My friends don't always follow what feels safe and comfortable for me. Some crowd me and have a much more relaxed approach to masks and being indoors. However clear I am about my own needs, I don't have the strength to insist on other people respecting them... ..the shift in expectations of others takes choice from me." – S, age 62*

*"I had certain family members expecting me to return to "normal" straight away and they couldn't understand my reluctance as far as they were concerned if the government says it was safe its safe whereas I tend to go along the scientific route more so this was very frustrating." – H.P, age 46*

## ***Invalidated***

For many, shielding compliance and anxiety about reintegrating was said to be met with judgments and minimising responses from friends, family, colleagues and employers.

Although some experienced support and understanding in their decisions, many felt labelled as ‘paranoid’ and felt the need to justify themselves by showing others evidence of the extent of their risk through shielding letters and online research.

*“... people's attitudes were that I was over reacting, paranoid and a bit of a nuisance...someone actually called me a hypocrite because they knew I was visiting shops. What they didn't know was the amount of mental risk assessing that went into each trip out. It felt like no-one cared and that I had to keep justifying myself.” – D.1, age 60*

*“I attended a webinar and found evidence to support what I had been told about my ongoing immune system. A senior colleague rolled their eyes when I discussed my concerns... I felt belittled, hurt and angry.” – D, age 52*

## **Domain 7. Impact of the ‘High Risk’ classification**

### ***Official advice to shield***

Relief: A subordinate theme of relief was identified in relation to official shielding advice and the felt safety this enabled. For some this was linked to the practical support offered to access essentials. There was also relief in relation to the official support to stay home from unsafe work environments. For some, receiving the letter validated the seriousness of the condition they were living with.

*“I was actually relieved, I was far more relaxed and felt much safer with us both being indoors. We didn't leave our house/garden for anything except hospital appointments.” –*

*S.P, age 43*

*“I was relieved that I received a letter telling me to shield as I knew that being on Immunosuppressants was a risk.” – M.Y, age 65*

*“If anything it made me feel a little bit special. The government chose me, amongst many others, to isolate myself from the world in order to protect myself. They must think at least I am worth protecting, so I was grateful.” – S.C, age 59*

**Aversion:** For some, receiving the letter was an aversive experience for the confirmation it provided about the real risks of covid-19 and for the restrictive nature of the advice. A minority had expected to be advised to shield but had hoped they might not be, and a small number of participants expressed having been shocked and/or disappointed by receiving the letter. There were several who described receiving this advice as highly unsettling.

*“Seeing it in black and white just made me feel more worried. Before receiving the letter I knew I should go careful and take precautions but this cemented a more deep rooted fear of what could happen if I caught it.” – P, age 57*

*“I was quite shocked and upset to receive my first shielding letter, especially as it came so late.” – L.P, age 32*

## ***Identity***

Two groups entered into discussions surrounding the impact of their 'vulnerability' label on their sense of self and identity. Many participants described a sense of having become useless to society, going from self-sufficient to dependent on others to survive. Some described having lost their sociable nature, and some felt made to feel like an outsider by friends and colleagues. There was a sense of grief and guilt communicated throughout these discussions; many felt they needed to make the decision to compromise their true nature to prioritise their own safety.

*"I regarded myself as assertive, positive, good at problem solving and useful to my family and society. Suddenly I needed to rely on others and unable to participate fully in my family, work and society." – J, age 62*

*"My workplace was very different; the staff had a 'we worked through covid' attitude and I was left to feel like an outsider." – A.X, age 40*

*"I used to be someone who would do anything to help anyone, now I'm selfish coz I've had to be to keep myself safe." – J.M, age 39*

## ***Mortality***

Many experienced an increased awareness of their own mortality and of the impact of their conditions in the face of their risk classification. This was particularly prevalent in group 1, where a discussion arose about experiences of being required to make advance treatment



decisions for in the event of infection. This was experienced as disturbing by those who shared in this discussion.

*“Shielding put the fear of dying into me; and I still haven’t shaken that fear.” – A.X, age 40*

*“Then, a call from the GP’s surgery, asking about resuscitation and ventilators, and how I most probably wouldn’t survive covid. I think it was then the seriousness of everything hit me.” – Q, age 61*

*“...that covid could basically kill me made me fearful and very anxious, and being called vulnerable really made me consider the risks of catching covid or other diseases... I think being classed as clinically extremely vulnerable made me actually feel like my health and disabilities really did make me a vulnerable person which was quite difficult.” – L.P, age 32*

### ***Societal Perceptions***

The pandemic left many feeling undervalued by society, seen as less worthy and expendable due to assumptions of a poor quality of life for people with underlying conditions. Some felt these perceptions were reflected in government communications which felt to intend to reassure the public with the notion that it was mostly individuals with underlying conditions dying. There was an awareness of the lack of representation of high risk groups in the media, and some experienced a sense of care diminishing as the pandemic progressed; many felt forgotten.

*“I read about a recent study where doctors rated the quality of life of disabled people as really low. I reckon they might look at me and think I have a low quality of life. But I love*

*life.... It makes me angry to think a stranger might look at me and just see the fact that I stay in bed most days and decide I have a low quality of life. It makes me scared too that they might make decisions about my health on that basis.” – T.L, age 61*

*“I too have marvelled at the selfishness of people . The horrible way they have dismissed deaths as ‘they had underlying issues. Or they were old or it was their fault’”. – J, age 62*

*“...it felt like we were expendable. Like my life didn’t matter because I’m ill anyway.” – A.X, age 40*

## Discussion

This study offers a qualitative exploration of the lived experiences of individuals classed as high risk and advised to shield during the covid-19 pandemic. The findings provide important insights into how these peoples’ experiences have shaped their perceptions of coercion and impacted their psychological wellbeing in the context of the intermittent advice to shield and wider public health preventative measures.

Although some described an aversive response to receiving shielding advice, the data suggests unanimous support for the wider restrictions and shielding policy itself, consistent with previous findings (Sloan et al., 2021). These policies were generally perceived as necessary and justified by the risk they were intended to mitigate and the data suggest all participants followed the shielding recommendations. The HBM (Rosenstock, 1974) proposes individuals are most likely to adopt recommended health-related behaviours when they believe there is significant risk of disease or illness and when they believe in the effectiveness

of the recommendations. The findings suggest these conditions were sufficiently fulfilled for the majority of participants, most of whom voiced feeling invested in mitigating their clinical vulnerability to covid-19 and confidence in the safety structures introduced to protect them. The findings also indicate positive perceptions of procedural justice in the application of the restrictive policies and minimal prevalence of felt pressure to abide by them. Many in fact felt relieved to receive shielding advice and believed they had freedom of choice and control over how they implemented it for their own protection. As such, although a small minority suggested their decision to shield felt internally pressured by the threat covid-19 posed to their health, broadly the findings support that the majority of participants did not feel coerced to shield (see Gardner et al., 1993; Simpson et al., 2020).

Embedded throughout the themes identified was an evident broader narrative around peoples' sense of safety from the feared virus, which seemed to evolve throughout the intermittent restrictions and official shielding advice. The findings suggest most perceived significant threat to their control over the maintenance of their personal safety when official shielding advice/support was lifted, accompanied by an expectation to return to 'normality'. For many this included returning to a work environment that was not felt to be covid-secure. Perceptions of coercion in this context appeared widespread amongst the majority of participants, most of whom believed it was not safe to re-integrate to the same extent as the rest of the public and did not agree with government advice to do so. This offers an important contribution to the small body of existing literature with high risk groups, which has similarly highlighted concerns around returning to work (Harris et al., 2020; Sloan et al., 2021).

Given the perceptions of coercion evident in most participants' reflections surrounding their expected reintegration, it is unsurprising that many participants experienced increased levels of distress and anxiety in this context, given findings from psychiatric literature that demonstrate a positive association with perceptions of coercion and distress (Gerle et al., 2019; Priebe et al., 2011). There were also many psychological challenges described to accompany shielding itself despite support for the policy. Similarly to previous shielding literature (e.g. Gessa & Price, 2021; Lasseter et al., 2022), for many this included feelings of loneliness, isolation, loss, and changes in mood and mental health. This is also consistent with literature focussed on the rest of the public during lockdowns (e.g. Buecker & Horstmann, 2021; Pai & Vella, 2021; Pierce et al., 2020) and for the present population likely reflects a combination of the inevitable impact of restricted liberties, isolation, and fears surrounding the pandemic itself. Although there were psychological adversities depicted during shielding, generally the appraised protection offered by the choice and support to shield was believed by some to mitigate potentially worse psychological consequences such as those experienced when shielding was lifted. There were several adaptive coping strategies applied to manage the challenges of shielding, including internal strategies which drew upon resilience such as practicing self-validation and compassion, and external strategies involving seeking support and connection from communities via social media.

As similarly reported in previous shielding literature (Sloan et al., 2021), some felt a shift in their identity where the need for shielding was accompanied by a transition from feeling independent and autonomous to dependant on others to survive and felt a reduced capacity to contribute to society. This is reflective of findings from research with people living with disabilities and people with long term health conditions, outside the context of the pandemic, (Lejzerowicz, 2017; Murugami, 2009; Wilson & Stock, 2019). For the participants in the

present study this appeared to be perpetuated by marginalising societal narratives around high risk groups and wider perceptions of disability and 'frailty'. Many felt viewed as less worthy and unimportant due to societal assumptions about quality of life and government communications distinguishing the deaths of 'healthy' people from people classified as 'high risk' in a perceived attempt to reassure the public. Accordingly, it is known that such stigma can have a significant impact on mental health for those with physical disabilities (Brown & Ciciurkaite, 2021; Silván-Ferrero et al., 2020), and that indeed medical professionals themselves hold assumptions about disability and reduced quality of life (Iezzoni et al., 2021). It is important to consider how these experiences and perceptions may have been impacted by others' varying adherence to the rules and guidance. Many felt this took away some of their control and choice in how and when they approached reintegration when shielding was lifted, as this was perceived by some to be highly dependent on the extent of others' compliance with the guidelines still in place. Some experienced the significance of their fears and anxieties surrounding covid-19 and their need to stay safe were minimised and invalidated. Perceptions of emotional invalidation has been linked to increased distress (Schreiber & Veilleux, 2022). These findings further support the presence of perceptions of coercion in relation to relaxing shielding outside the context of work.

The introduction of the shielding policy was accompanied by a sense of being actively considered and protected by the government, although as similarly depicted in previous research, some perceived their initial response to the pandemic to have been too slow (Sloan et al., 2021). The findings also demonstrate a high prevalence of negative perceptions of the government in their decision-making as the pandemic progressed, particularly with regards to the lifting of shielding which was felt by many to have been premature. Similar expressions

of distrust towards the government during the pandemic have been demonstrated in literature focussed on high risk groups and the general population (Davies et al., 2021; Sloan et al., 2021).

The psychiatric literature demonstrates how perceptions of coercion are more likely to be reported where individuals have felt excluded from decisions relating to their care and where treatment is viewed as ineffective (Katsakou et al., 2011; Sampogna et al., 2019). The evident disapproval of government decisions with regards to the lifting of shielding combined with a felt sense of not being heard by decision-makers is likely to contribute to perceptions of coercion experienced by those who felt pressured and limited choice around their re-integration behaviours.

Many of the present findings are consistent with the theory behind the transactional model of stress and coping (Lazarus & Folkman, 1984). It is clear that participants' cognitive appraisals of their given situation in the context of active legislation and guidance at various timepoints had an important impact on people's psychological wellbeing. It is also evident that personal evaluations of one's resources to cope with these situations played a key role in the extent of distress experienced. For example, most recognised a reduction in distress once reliable access to essentials was established, albeit the difficulties some faced accessing particular items. Many also acknowledged how their personal circumstances, including safe access to the outdoors, retirement and financial stability, enabled their ability to shield and to maintain a safe environment in which to apply effective coping strategies. The lifting of shielding brought about threatening appraisals about the impending event, including perceptions of coercion, and many experienced a reduced perceived capacity for coping with this, particularly where there was little felt control over reintegrating. Many sought

emotional support from safe relationships where possible, and there were also many descriptions of practical solutions, including seeking occupational health referrals to maintain safety and taking gradual steps to reintegrate, informed by local covid-19 data. Research applying the TSC has shown how such adaptive emotion-focussed and problem-focussed coping strategies are associated with better psychological wellbeing outcomes (Miller Smedema et al., 2010; Sagone & Elvira De Caroli, 2014). The individuals who participated broadly showed a remarkable capacity to care for themselves under exceptional circumstances; these findings speak to the real strength and resilience of a group who have felt undervalued and indeed underestimated by society.

### *Strengths and Limitations*

Participants were purposively selected for recruitment from the wider UK study; a sampling method suited to qualitative inquiry, which aims to understand and clarify human subjective lived experience rather than to provide a representative picture of a wider population (Polkinghorne, 2005). However, it should be acknowledged that with respondents to adverts predominantly female, all from white ethnic backgrounds, the voices represented in this study cannot necessarily speak to the experiences of the broad spectrum of individuals advised to shield in the UK. The lack of representation of the voices, experiences, and strengths of those from marginalised ethnic backgrounds is a particularly important limitation for consideration, given the vast literature surrounding the significant disproportionate health, social, and ethical impact of the pandemic on these individuals (Mattos dos Santos, 2020; Proto & Quintana-Domeque, 2021). As such, the problematic underrepresentation and barriers to recruiting ethnically minoritised and other marginalised groups in psychological research is increasingly acknowledged (Crittenden-Ward et al., 2022). This issue was evident

in the failure of the researcher to attract participants from marginalised ethnic backgrounds during attempts to extend recruitment beyond the wider study survey to increase diversity in the sample, and likely partly reflects a wider problem with regards to the typical methods and approaches employed by westernised, white-presenting researchers in recruiting participants from diverse and marginalised communities. The recruitment process was also unlikely to have reached those who do not use social media platforms, who may indeed have had a very different experience of shielding given the emphasis placed on social media use as a coping strategy. It is clear this is a significant wider issue in the field of psychological and health research (Arigo et al., 2018).

The process of participation in the AVFGs was valued by many participants for the accessible and anonymous space it provided to share stories and voice difficult feelings and perceptions surrounding their experiences. It must be acknowledged, however, that this method also inherently yields a number of limitations. Firstly, it is more difficult to capture spontaneous, raw reflections and emotions where participants may be more carefully considered in taking time writing their responses. As in previous research applying AVFGs (e.g. Gordon et al., 2021), there was variance in the level of engagement with the AVFGs between participants and between groups. Some participants' responses were long and in-depth, whereas others were more brief, direct answers to questions. Some posted more frequently and elaborated on their reflections via interactions with others, and some kept their responses limited to explicit questions and posted less. These differences were most notably evident in group 3, where responses were shorter, more direct in answering questions, and participants were less interactive with one another compared with the first two groups. Group 3 were largely comprised of participants who responded to recruitment adverts after their third receipt of the invitation, which perhaps reflected less of a personal need or investment in sharing their



experiences than the participants in the other groups, who all responded quickly to the adverts. We must also consider the culture and dynamics of each AVFG; both group 1 and 2 began with the first respondent offering a long, in-depth entry, perhaps 'setting the tone' for other participants. By comparison, group 3 began with shorter answers and reflections from participants, again, likely to influence following participants' responses. It is therefore important to consider how the themes and narratives identified may have been implicitly shaped by more dominant voices.

Likewise, the researcher's own role in the data collection and analysis plays an important part in shaping the findings, as researchers inevitably enter the research process with their own experiences, perceptions, assumptions and beliefs in the context of their own lived experience of the pandemic and more broadly (Walsh, 1995). This is not necessarily a limitation as it is inherent in qualitative research and can be a highly valuable component, though it is important to acknowledge. One example with regards to the researcher's pre-existing assumptions and their impact on data collection is evident in the decision not to collect additional data from participants about their specific health conditions or personal level of risk. Although this decision may have been influenced by assumptions and concerns around requesting 'too much' sensitive personal information, the findings highlight the importance of personal context in participants' pandemic experiences. Therefore, by further illuminating these health aspects of respondents' context the findings may have offered more of a depth of understanding in terms of pre-existing health experiences, pain, suffering, and resilience and how these will have inevitably shaped experiences of shielding, and more broadly, of the pandemic.

With the specific focus on eliciting responses relating to perceptions of coercion, given knowledge of the emerging findings from the wider Covid-19 Wellbeing study (Ranieri et al., 2021), it must be considered how the language used to elicit responses, such as use of the words 'choice', 'control', and 'pressure', may also have shaped the language applied by the participants in how they shared their experiences and thus the themes identified. However, it should be noted that many communicated their perceptions at times without explicit reference of the researchers' own words. There are also important implications to consider when conducting outsider research, particularly where marginalised and stigmatised groups are concerned (Wigginton & Setchell, 2016). These issues are further explored in Part Three. Despite these considerations, this data collection method yielded extremely rich, quality data from a population who are not currently well-represented in pandemic research, and it was a highly beneficial method in the context of isolation.

### *Implications*

Some participants felt their voices had become diminished throughout the dominant public narratives, as though their sacrifices and challenges were forgotten. This speaks to the importance of better representing individuals at increased vulnerability in future serious infectious disease outbreaks, and creating platforms for these individuals to contribute their stories and provide ongoing representative consultation to decision makers. Participants demonstrated great appreciation for the practical and community support that accompanied the shielding policy, although the findings also indicate a lack of perceived support and consideration for reintegrating. Future policy makers should incorporate this notion into their strategy for the lifting of preventative measures in the future and consider additional targeted practical and psychological support for those advised to take extra precautions such

as those shielding. Similarly, the furlough scheme was perceived to overlook the needs of high risk groups, many of whom were afforded only statutory sick pay which created additional financial burdens and pressure to later return to work when it felt unsafe. This should also be carefully considered if similar financial support is offered to employers in the future.

Communication of rules and guidance was found to be lacking in thought and clarity, a perception shared by many affected by the pandemic (Abrams et al., 2021). Given the rise in globalisation and the increased likelihood of future pandemics (Antràs et al., 2020), policy makers should carefully and pre-emptively consider the conditions required for each preventative policy to ensure the timeliness and effective communication of their instigation.

Finally, some participants expressed gratitude for the anonymous discussion platform, and communicated a sense that a space for peer-support and validation had been missing. Local authorities and health services should consider the targeted inclusion of wellbeing support services for high risk groups in the future.

### *Future directions*

The covid-19 pandemic prompted a wealth of research surrounding the implications for those impacted, although the experiences of shielding groups remain underrepresented. The present study contributes important insights into the experiences of shielding itself and the acute impact of lifting restrictions. Now that the UK government response has moved to 'Living with COVID-19', it is crucial that the psychological implications this may yield for high risk individuals is examined. Efforts should also be made to examine the impact of intermittent shielding advice on further marginalised groups given evidence of the

disproportionate pandemic impact on individuals from minoritised and economically deprived backgrounds (Mattos dos Santos, 2020; Proto & Quintana-Domeque, 2021).

To the researcher's knowledge, this is the first study that has explored the concept of perceived coercion in the context of restrictive safety structures being removed. This highlights an important avenue for future psychiatric research exploring perceptions of coercion in the context of hospital discharge.

### *Conclusion*

The covid-19 pandemic presented global public health and societal challenges of unprecedented proportions, requiring governments to intermittently adopt highly restrictive measures and targeted advice for those at increased risk in order to reduce the spread and mitigate harm. This study provides important insight into the experiences of those who were classified as high risk and advised to shield during various periods of the pandemic, and highlights the presence of perceptions of coercion and increased distress as choice and control was felt to become diminished for many participants when official shielding advice was lifted. The findings yield key considerations for policy-makers and health service providers in the preparation for further serious infectious disease outbreaks, which are increasing in likelihood due to the substantial rise in globalisation.

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## Part Three: Critical Appraisal

## Introduction

This paper offers some reflections and critical considerations with regards to the process of conducting the qualitative research presented in Part Two, which explored the experiences, perceptions, and psychological wellbeing of individuals classified as high risk and advised to shield during the covid-19 pandemic. This study particularly sought to gain an understanding of the experiences of the easing of public health restrictions and lifting of official shielding advice, and to explore perceptions of coercion in this context. The empirical work forms a qualitative component of the wider Covid-19 Wellbeing Study (Ranieri et al., 2021), and offers an important contribution to the body of literature focussed on the covid-19 pandemic, which is limited in its attention to the experiences of individuals classed as high risk.

In this critical appraisal I first consider the implications of conducting 'outsider' research and reflect on my research decisions surrounding this. I also provide some considerations with regards to my approach and felt alignment to participants during the process, further contextualising my position as a researcher and acknowledging the influence of my own perceptions, assumptions, and experiences in this study. Issues relating to my recruitment strategy and the sample of participants this yielded for the study are discussed. Finally, I provide some personal reflections surrounding the findings and their implications, and consider the pandemic context in which the research was conducted.

## Conducting 'Outsider' Research

Although as a member of the UK public I was required to abide by lockdown rules and other covid-19 restrictions and protective behaviours, I am able-bodied with no significant known underlying health issues, did not perceive myself as at an increased vulnerability to the virus and did not receive advice to shield. This positions me as an 'outsider' as a researcher in this project, particularly in the sense that I do not possess the health attributes that were felt to be further stigmatised during the pandemic (Wigginton & Setchell, 2016), and did not perceive the lifting of restrictions to pose a significant threat to my health. On the contrary, I experienced a sense of desperation to return to 'normality', to mix with friends and family, and to return to work in person without the burden of a fear for my life. Issues of both privilege and power are intrinsic in the position of an outsider researcher, particularly in a project that explores the experiences of a marginalised population (Link & Phelan, 2001), and with this social influence in mind, how my position as a researcher may have shaped participant engagement is important to consider.

An outsider is inherently likely to bring with them a level of naivety in their understanding of a given topic, which can be helpful for prompting participants to illuminate nuanced elements of their experiences they may have given less thought to or 'taken for granted' (LaSala, 2003). The added curiosity that may come with this outsider-ness is also argued to benefit the interview process and reinforce the importance of participants sharing their experiences (Hayfield & Huxley, 2015). However, one of the main challenges in conducting outsider research is the potential to misunderstand or misrepresent the experiences of participants, which can result in the perpetuation of societal assumptions and stigma (Link & Phelan, 2001; Wigginton & Setchell, 2016). My position as an outsider was therefore very

much held in mind throughout the research process, although acknowledging there were clear parallels in the data to my own experiences and perceptions of isolation and government management of the pandemic despite the circumstantial differences. The input of individuals who had received official advice to shield in the formation of the focus group questions was thus crucial to the research process. I found this raised important issues and questions I had not previously thought about and it was rewarding to observe these issues further illuminated in the data.

### *Outsider-ness Disclosure*

It is important to acknowledge that as the researcher I remained fairly anonymous myself in that I did not actively disclose my 'outsider' status, and due to the nature of the data collection modality it was not possible for participants to gather or confirm information with regards to my age or health status through seeing me. Although assumptions could have been made based on the minimal information available (e.g. conducting doctorate research, my name), this largely left the participants naïve to my circumstances during the pandemic and this may have impacted the way in which I was perceived as a researcher and the extent and quality of engagement.

Researcher disclosure to participants is a debated topic; some promote it as an important way to build trust and increase openness during the interview/focus group process (e.g. Campbell & Wasco, 2000), whilst others believe limiting disclosure may allow the researcher to maintain a neutral space into which participants can project their raw views, and some also argue for the importance of remaining personally detached from the research for wellbeing reasons (Dickson-Swift et al., 2006; Wigginton & Setchell, 2016). Although as a

clinical psychologist in training I am aware of the therapeutic value of some disclosure within reason where clinically beneficial, my non-disclosure in this context perhaps reflects my previous research experience which has predominantly applied a quantitative methodology and a positivist epistemological stance. Through this I had come to understand my objectivity as a researcher to be central to obtaining scientific knowledge, and it was only during the facilitation of the focus groups that I began to consider whether disclosing my health status and pandemic circumstances might have added value to the process and enhanced the felt safeness for participants sharing their stories. Nevertheless, it was clear the focus groups provided a space that yielded rich, quality contributions where participants seemingly felt safe to freely express their views with regards to the government and the behaviours of those not shielding. My non-disclosure may have played a role in enabling the space to become the valued platform that participants ultimately perceived it was. This issue of outsider disclosure is an important learning point from the research process, and in the future this is something that should be more carefully considered, particularly for qualitative research.

### **Researcher Approach and Alignment: implications**

It is inevitable that the researcher enters the research process, regardless of the methodology or epistemological stance, with a pre-existing set of assumptions and expectations, both explicit and implicit, with regard to a given subject matter (Walsh, 1995). My immersion in the relevant literature and personal context in addition to my own pandemic experiences and perceptions had important implications for the processes of data collection and analysis in that my approach had inherent potential to shape these processes in a way that could have differed somewhat from another researcher entering the process

with different preconceptions. Bracketing and keeping a reflective log were important processes for monitoring my own biases and assumptions at the beginning, and as they arose or became seemingly confirmed or disconfirmed at various phases of the research process. However, it is argued that instead of researcher assumptions and context being an obstacle to understanding, such researcher preconceptions may form the foundation from which a phenomenon can be effectively and meaningfully made sense of and represented (Giorgi, 1970). With awareness of my preconceptions and their role in the research process, I made an active decision to code at the semantic, rather than latent, level during the initial phase of analysis, taking participants' language as representing real world constructs so to best accurately capture participants' communications, progressing to a more deductive approach only when broader themes took full form. With my own context in mind and given my relative inexperience in applying a qualitative methodology it felt important to approach each phase of thematic analysis specified by Braun & Clarke (2006) in a highly systematic manner to maximise consistency and validity of the analysis. Yet, it is still necessary to contextualise the findings within my own frame of reference as a reflexive researcher.

As the focus groups went on, I found myself increasingly aligned with the participants in terms of their views and perceptions, and at times internally shared in their angers and frustrations and empathised with their emotional experiences. Although I maintained efforts to withhold this from my interactions with the focus groups or unintentionally lapse into leading questions that may reflect my own biases or assumptions, it must be considered how my attempts to communicate that I was really hearing the participants, with a view to reinforce continued engagement and validate difficult experiences, may have inadvertently offered some subtle insight for participants into my own perceptions or judgments of the

navigation of the pandemic by the government and by the rest of the public. It cannot be ignored how this in turn may have shaped responses, as much as this may have supported participants to feel heard and continue offering their thoughts.

### **Recruitment and the study sample**

One of the main challenges faced in this project was in enhancing the diversity of participants, particularly with regards to gender, ethnic background and social context. Participants were recruited from those who took part in the wider UK Covid-19 Wellbeing Study survey and indicated their consent to be contacted for further participation. It was noted that the vast majority of those who took part in this wider study and disclosed their risk status had identified themselves as ethnically white and female so it was acknowledged that there may be challenges to representation of diversity at the point of recruitment. With this and its potential implications in mind, efforts were made to expand the recruitment pool through social media adverts targeting Facebook group pages for people who have shielded. This included seeking permission from specific groups formed by and for people from Black, Asian and minoritised ethnic backgrounds to post adverts. There was great support from group admins to advertise the project, although unfortunately this did not generate further interest in participation and ultimately no participants were recruited from outside of the wider study.

There are already issues associated with recruiting via social media platforms as this method likely yields only respondents who actively engage with these spaces and has potential to bias the sample and thus the findings (Benedict et al., 2019). Nevertheless, social media is increasingly used as a recruitment tool, particularly for degree dissertation or thesis projects,

for the advantages in terms of its far reach and low cost (Topolovec-Vranic & Natarajan, 2016; Whitaker et al., 2017). For this particular project, the use of Asynchronous Virtual Focus Groups (AVFGs) was felt to be highly suitable given the pandemic-related isolation context and the high risk status of individuals participating, and in using this method computer literacy was an assumed requirement to enable engagement in the groups. Given the extent of value participants attributed to their use of social media during the pandemic to stay connected to friends, family, online communities and families and to cope with the challenges of shielding, it is worth acknowledging that recruitment advertisements could only reach those already accessing social media. Millions in the UK were advised to shield and it is important to consider how those who may not have accessed social media as much or at all during their isolation might have experienced, perceived, and coped with the pandemic differently. During the pandemic social media use reached unparalleled heights (Fischer, 2020), and in many ways is considered to have played a 'buffering' role in determining people's resilience and ability to cope during with the challenges of lockdown (Marzouki et al., 2021). To my knowledge there is no covid-19 research focussed on the experience of those who have not utilised, or had access to, social media during this period. This may indeed be a difficult minority to reach, but given the emphasis placed on social media for coping with isolation we must hold in mind the potential differences in experiences of those who were not able to maintain connection with the outside world in this way.

As briefly highlighted in the empirical paper, health and psychology researchers commonly face barriers to recruiting participants from minoritised ethnic backgrounds, and until recent decades this has gone relatively unacknowledged, with the development of widely accepted and applied psychological theory/models derived mainly from research with predominantly



white samples (Roberts et al., 2020). This represents a problem, and it is important to recognise the implications for this particular study. We know that race and culture plays an important role in our identity and how we develop in terms of our perceptions, beliefs, thoughts, values, general behaviours, and health-related behaviours (Roberts & Rizzo, 2020; Reiter & Katz, 2021). We observed an increased media emphasis and awareness of racial inequalities during the pandemic, with the murder of George Floyd prompting unprecedented social media discourse on race and racism (Nguyen et al., 2021). As discussed in Part One and Two, there was also evidence for the disproportionate impact of the virus itself on the health and mortality of people from ethnically minoritised backgrounds, with ethnic background later included in the risk assessment for increased covid-19 vulnerability. As we might imagine, racial trauma and stressors are thought to have been exacerbated and magnified during this period (Liu & Modir, 2020). Adding the experiences and challenges associated with a high risk status and advice to shield, people further marginalised in UK society due to their ethnicity may have illuminated a range of additional, potentially different experiences, perceptions, strengths, and coping strategies to those voiced by the sample in this study.

We must also acknowledge that this study captured the experiences of a majority female sample, with just three men out of twenty-four participants. Research indicates there were gender differences in distress and coping strategies during the pandemic (e.g. Prowse et al., 2021), and the literature also suggests females were more likely to report more stringent compliance with restrictions than males (Brouard et al., 2020). This highlights important considerations for gender differences with regards to pandemic experiences, and although

the qualitative data did not particularly illuminate any salient gender-based differences, it is worth noting the possible implications of the relative lack of male representation.

My project aimed to qualitatively explore the subjective lived experiences of the individuals partaking in the research and does not claim to be directly generalisable to the diverse range of individuals who were advised to shield during the pandemic. However, it is important to acknowledge and reflect on the shortfalls associated with the lack of diversity in the sample and consider this further during the design and recruitment phases of future projects.

## **Personal reflections**

### *The findings*

Many of the findings yielded by this study have been in line with my expectations based on the existing literature and on my observations during the pandemic, although there have been some challenges to my original assumptions in terms of the great magnitude of impact of the lifting of restrictions for this group. It is clear that further research is required to understand the experiences of shielding groups further on into the pandemic, considering the current UK Government response of 'Living with Covid-19', with all restrictions and guidance dropped, including the requirement to isolate following a positive covid-19 test. We must also consider how the cost of living crisis and ongoing political unrest may intersect with this context.

The finding that there is potential to experience perceptions of coercion in the context of safety structures being removed is one I view as of great importance for future investigation. Much of my pre-training experience was within adolescent psychiatric inpatient settings. We

know that there is unfortunately an increased risk of suicide attempts following discharge from psychiatric hospital according to adult mental health literature (for a meta-analysis, see Chung et al., 2017). During my time working in these contexts I certainly observed some young people to become highly distressed by the prospect of discharge back into the community, and although many eagerly left hospital with a sense of achievement and/or a readiness to return to their lives, there were those who challenged discharge decisions and said they did not yet feel safe to leave hospital. This is of course a very complex situation to manage, as there are many reasons psychiatric hospitalisation should be limited in many cases. It is interesting, however, that to my knowledge there is no research examining how perceptions of choice, control, procedural justice and coercion play into these experiences, and how they play into what a person goes through following their discharge from hospital. I feel this is a highly important avenue for future examination.

### *Conducting the AVFGs in the context of an active pandemic*

The time at which the focus groups were held captured a significant period of the pandemic during which the 'outside world' was opening up and returning to normality, with first and second vaccine doses offered to high risk groups and healthcare professionals such as myself and 'eat out to help out' programmes initiated to support the economy, increasing social mixing. Official shielding advice had ended during the month prior to data collection, and it was a purposeful decision to begin the focus groups at this time in order to obtain active feelings and ongoing experiences with regards to the easing of restrictions and lifting of shielding guidance so that any perceptions of coercion or distress in this context could be potentially illuminated. We must hold in mind that findings may have differed had the research taken place at an earlier or later point in the pandemic.

Despite my immersion in the literature, particularly with the health belief model (Rosenstock, 1974) in mind, I still found myself initially somewhat surprised to hear how many participants had continued their shielding behaviours following the official lifting of advice, although this makes a lot of sense on reflection. It was moving and upsetting to hear how fearful participants had experienced it where they had felt pressures from friends, family and employers and a lack of choice in physically reintegrating. This added important perspective to my own felt sense of relief and delight in the easing of the restrictions, and I felt the need to increase the stringency of my own compliance with the guidance and remind myself that the risks are still around for many people despite the encouragement to go out. Like participants, during this period I too experienced eye rolls and perceived judgment from some friends and acquaintances when I declined invitations to events which felt inappropriate given the spreading of the new variants, or declined hugs, committed to mask-wearing, and expressed discomfort where guidance was not being adhered to. This magnified what I was hearing from participants in terms of their sense of being unconsidered by the rest of the general public. With this all in mind, I was also struck and moved another overarching theme which, on reflection, really comes through from all participants in the data: a theme of resilience. Participants seemed to carry with them a context of pre-existing hardship, particularly with relation to their health conditions, mental health experiences, and for some, previous experiences of having isolated when immune-suppressed. The strengths displayed and attitudes communicated around letting the emotions 'be', prioritising self-care and finding moments of hope and light in their experiences when they were most difficult was a wonderful thing to bear witness to as a researcher. A year on from data collection, I find myself wondering what the past 12 months has been like for participants – have the felt pressures eased or have they persisted? Has the perceived risk diminished or is the outside

world still as fearful? Have they continued shielding or have they felt able to return to some normality? And importantly, are they all still around?

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## Appendices

## Appendix A: Ethical approval letter for the wider COVID-19 Wellbeing Study



15<sup>th</sup> July 2020

Professor Sunjeev Kamboj  
Department of Clinical, Educational and Health Psychology  
UCL

Cc: Professor Sarah Edwards, Dr Veronica Ranieri & Ms Andrea Stoltenberg

Dear Professor Kamboj

**Notification of Ethics Approval with Provisos**

**Project ID/Title: 7335/004: The COVID-19 Wellbeing Study: Perceived coercion and psychological wellb the COVID-19 pandemic**

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **15<sup>th</sup> July 2021**.

**Ethical approval is granted on the following provisos:**

1. Clarify if the anonymised data that will be retained for 10 years will be made available to other researchers during this time, and if so this needs to be made explicit in the information sheets and consent forms. Please clarify this before the study commences.
2. Norwegian ethical approval is obtained and submitted to us for record before the study commences.

As you will be submitting a modification at a later stage to include Ireland in this study, please submit the ethical approval from Dundalk Institute of Technology University when you submit the amendment request.

Also, in view of the fast developments of the pandemic, the numerous projects being initiated and the constantly changing framework, please provide us with regular updates **every 3 months** regarding the ethical aspects of your project and the specific problems (if any) that you have encountered. At the end of the study, as part of the final report you have to submit to the UCL REC, please include alongside a brief outline of the research outcomes, any experiences which would be valuable for informing the fast-track COVID review process, and in turn subsequent fast-tracked studies.

Ethical approval is also subject to the following conditions:

**Notification of Amendments to the Research**

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical

Office of the Vice Provost Research, 2 Tavilton Street  
University College London  
Tel: +44 (0)20 7679 8717  
Email: [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)  
<http://ethics.grad.ucl.ac.uk/>

approval by completing an 'Amendment Approval Request Form'  
<http://ethics.grad.ucl.ac.uk/responsibilities.php>

**Adverse Event Reporting – Serious and Non-Serious**

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

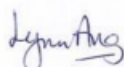
**Final Report**

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc. In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: <https://www.ucl.ac.uk/srs/file/579>
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely



**Professor Lynn Ang**  
**Joint Chair, UCL Research Ethics Committee**

Appendix B: Ethical approval - amendments approved for the present study

## APPROVED: Amendment request form project ID 7335/004

 You replied on Wed 21/04/2021 11:41





VPRO.Ethics

To: Harris, Josephine



Wed 21/04/2021 11:39



2 attachments (120 KB)  Save all to OneDrive - University College London  Download all

Dear Josie

The UCL REC has now approved your attached amendment request. Please take this email as confirmation of that approval.

**IMPORTANT: For projects collecting personal data only**

You should inform the Data Protection Team – [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk) of your proposed amendments, including requests to extend ethics approval for an additional period.

Best wishes, Helen

Helen Dougal  
UCL Research Ethics Co-ordinator  
Office of the Vice-Provost (Research)  
University College London  
2 Taviton Street, London, WC1H 0BT  
Email: [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)

## Appendix C: Participant Region



SPSS Output for Participant Country and Regional Frequency Breakdowns

**UKCountry**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	England	20	83.3	83.3	83.3
	Scotland	2	8.3	8.3	91.7
	Wales	2	8.3	8.3	100.0
	Total	24	100.0	100.0	

**Location**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	East Anglia	3	12.5	12.5	12.5
	East Midlands	3	12.5	12.5	25.0
	Greater London	4	16.7	16.7	41.7
	North East	3	12.5	12.5	54.2
	North West	2	8.3	8.3	62.5
	Scotland	2	8.3	8.3	70.8
	South East	2	8.3	8.3	79.2
	South West	3	12.5	12.5	91.7
	Wales	2	8.3	8.3	100.0
	Total	24	100.0	100.0	

## Appendix D: Participants' Ages

SPSS Output for Participant Age Descriptive Statistics

**Descriptive Statistics**

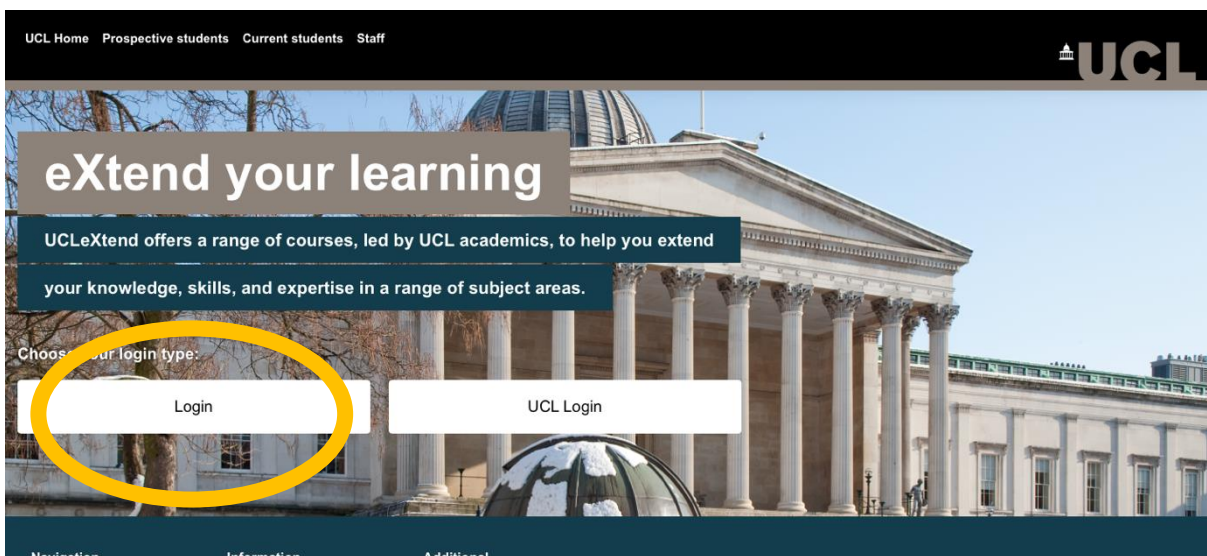
	N	Minimum	Maximum	Mean	Std. Deviation
Age	24	32	76	56.79	11.736
Valid N (listwise)	24				

## Appendix E: Guidance for using UCL Extend

# Guidance for using Extend

Thank you for taking part in our study!

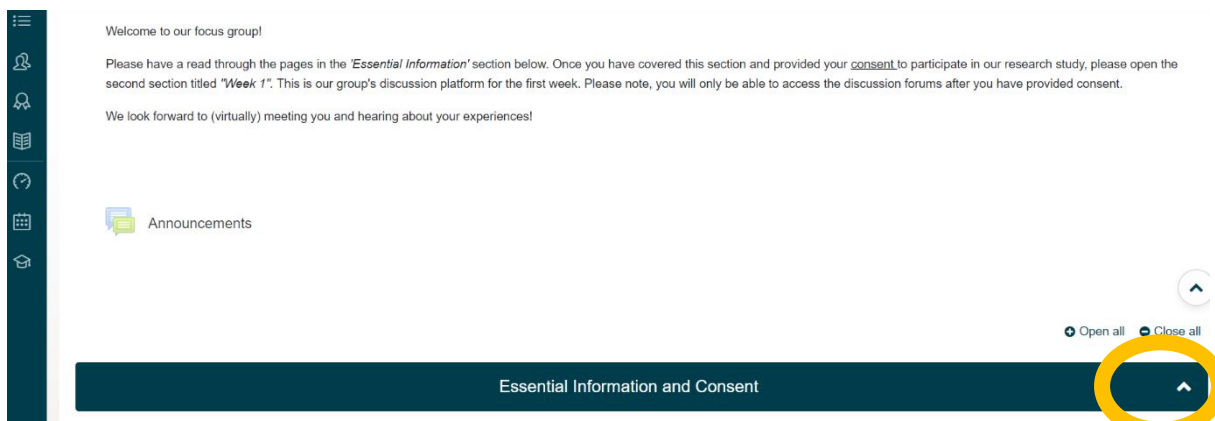
1. To access the online site please visit <https://extend.ucl.ac.uk> Upon reaching this page, you will be asked to log in. Please log in via the tab on the left using your email address and the temporary password UCL eXtend sent you.



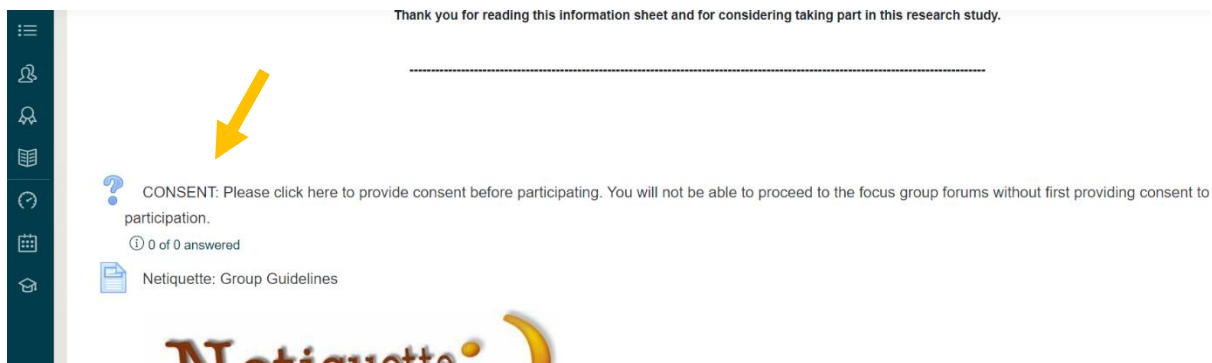
2. When you log on, please click on the 'course' that appears. Upon clicking in, you will be greeted by this page!



Below that, you will see a tab titled 'Essential Information and Consent'. If you click on the arrow of the tab, it will open up some essential information for the study: a copy of the information sheet for you to access anytime, a consent form, some netiquette guidelines and some useful contact information.



3. Please could you read through the information in this section. To provide your consent to participant please click the 'CONSENT' link indicated below.



Once you have read through the consent information **tick the consent box** if you agree to take part in the study.

- I understand that my information may be subject to review by responsible individuals from University College London for monitoring and audit purpose
- I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.
- I understand that no promise or guarantee of benefits have been made to encourage me to participate.
- I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.

The results of this activity will not be published after you answer.

Yes: I consent to participation

Save my choice

4. After that, you are ready to go! The first week's discussion forum will be visible from the **agreed start date** of your focus group. Once it is available please click onto your first week's topic. Please note, you will not be able to access the forum until you have provided consent.

Week 1

Restricted Not available unless: The activity CONSENT. Please click here to provide consent before participating. You will not be able to proceed to the focus group forums without first providing consent to participation. **is marked complete**

Welcome to our first focus group discussion!

Below you will find a link to this week's discussion platform titled 'Week 1: Views and experiences of shielding'. Click the link and you will be directed to the discussion page.

Week 1: Views and experiences of shielding

A question will appear as a topic as shown in the example below. Do not use the 'add a new topic' function. To answer the questions, please click on 'Discuss this topic'...

Add a new topic

**Example Question**  
by Josephine E Harris - Sunday, 9 May 2021, 9:01 PM

Example

Permalink Edit Delete

Discuss this topic (0 replies so far)

...and then click 'reply'.

### Example Question

Settings ▾

Display replies in nested form ▾

Move this discussion to ... ▾

Move



#### Example Question

by Josephine E Harris - Sunday, 9 May 2021, 9:01 PM

Example

Permalink

Edit

Delete

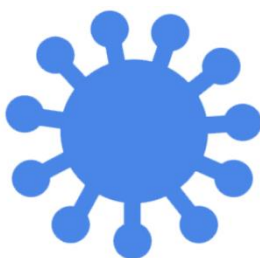
Reply

Happy writing!

If you run into any difficulties, please email me on [REDACTED]



## Appendix F: Participant Information Sheet



## THE COVID-19 WELLBEING STUDY

### **Participant Information Sheet for the Online Focus Groups**

UCL Research Ethics Committee Approval ID Number: 7335/004

**Title of Study:**

*The COVID-19 Wellbeing Study*

Perceived coercion and psychological wellbeing during the COVID-19 pandemic

**Department:**

Science & Technology Studies / Psychology & Language Sciences

**Name and Contact Details of the Researcher(s):**

Miss Josephine Harris T: [REDACTED]

Dr Veronica Ranieri T: [REDACTED]

Ms Andrea Stoltenberg T: [REDACTED]

Prof Sarah Edwards [REDACTED]

Prof Sunjeev Kamboj [REDACTED]

---

*You are being invited to take part in a research project. Before you decide, it is important for you to understand why the research is being done and what participation will involve. Please take your time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. The data collected for this project will also form part of a clinical psychology doctoral thesis for Josephine Harris. Thank you for reading this.*

**1. What is the project's purpose?**

The aim of the study is to understand the lived experiences of those who have been identified as extremely clinically vulnerable and instructed to stay home and 'shield' during the COVID-19 pandemic. We would like to primarily understand how these experiences have impacted on your perceptions of coercion and psychological wellbeing resulting from the isolation of shielding and wider restrictive measures during the COVID-19 pandemic. Previous research has identified that an individual's perceptions or appraisal of a situation may impact on their psychological wellbeing and coping mechanisms. When a situation is perceived negatively, it can lead to experiences of psychological distress and differences in the type or frequency of coping mechanisms we use to help manage the situation. We are, therefore, interested in how you experienced the instructions to shield and the extent to which you perceived such government imposed precautions as coercive or pressured, and we are also interested in your psychological wellbeing.

**2. Why have I been chosen?**

We are inviting you to take part as someone who has identified as living with a condition that is considered to place you at an increased risk of severe illness if you catch COVID-19, and as someone who has therefore received instructions to shield during the pandemic. We are inviting individuals aged 18 years or older who have been instructed to shield at various points during the COVID-19 pandemic and who are ordinarily resident in the UK to participate. We are asking you to take part in an online focus group to better understand what has shaped your personal perceptions regarding these restrictive precautions.

**3. Do I have to take part?**

Participation in this study is voluntary. You may discontinue participating in the focus group at any time without giving a reason.

**4. What will happen to me if I take part?**

If you would like to take part, we would ask that you take part in a three-week focus group hosted online with 6-9 other individuals. You will not be able to see the other participants though will be able to interact with them in writing. Over the course of three weeks, we will post some questions onto an online platform that is accessible only to the participants and the researchers. The questions will ask about your experiences and perceptions regarding instructions to stay home and wider restrictions and how your experiences have impacted on your emotional wellbeing. We ask that you kindly write about your experiences and views on this platform and, if you like, interact with what other participants say too. You may write as little or as much as you like and can access the online platform at any time of the day or night.

**5. What are the possible disadvantages and risks of taking part?**

We do not expect that taking part in the online focus group will place you at risk of harm. However, it is possible that you may feel some emotional distress during the study due to the nature of the topic. Should you experience significant distress, arising during or as a consequence of the research, please tell us. We will urge you to contact a health professional such as your General Practitioner and can redirect you to services available in your area. On our website [www.thecovid19wellbeingstudy.org](http://www.thecovid19wellbeingstudy.org) you will also be able to find multiple contact details for organisations providing support, such as the Samaritans (phone number: 116 123).

**6. What are the possible benefits of taking part?**

Whilst there are no immediate benefits for those participating in the project, participants from previous studies that used this method reported that they found it helpful to write down their experiences and share these with others who could relate. We hope that this work will help shape future clinical practice, government policy, and research, in relation to supporting individuals during pandemics.

**7. What if something goes wrong?**

Should you encounter any difficulties during the online focus group, please contact Josephine at [REDACTED]

Should you have queries regarding the overall conduct of the study, please contact Sarah at [REDACTED] or Sunjeev at [REDACTED]

Should you feel that your concern is not adequately addressed by the research team and wish to raise a complaint, please contact the Chair of the UCL Research Ethics Committee at [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)

**8. Will my taking part in this project be kept confidential?**

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications. Any identifiable information (ie. your email) will be stored on UCL's Data Safe Haven, a GDPR-compliant, encrypted system for the duration of the study. The data will be analysed by the research team.

#### **9. Limits to confidentiality**

We would ask you and your fellow online focus group participants to respect each other's confidentiality and not divulge information about each other or content from the focus group to individuals outside of the focus group. Confidentiality will be respected by the researchers unless there are compelling and legitimate reasons for this to be breached, such as danger to yourself. If this was the case, we would inform you of any decisions that might limit your confidentiality.

#### **10. What will happen to the results of the research project?**

The results of this research may feature in peer-reviewed publications, national or international conferences or media. You will not be able to be identified in any ensuing reports or publications. We will add any outputs from the study onto our website for you to access once analysed and written.

#### **11. What if I change my mind and would like to withdraw my information?**

You will be able to withdraw your data until these have been analysed and anonymised. After the data have been analysed and anonymised, we will be unable to identify you from the analysis to withdraw your data. Should you wish to withdraw your data, please email this request in writing to Josephine at [REDACTED]

#### **12. Local Data Protection Privacy Notice**

##### **Notice:**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice found at <https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies>

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows: age, geographical region, employment status, psychological and physical health, and healthcare resource usage

The lawful basis that would be used to process your *personal data* will be performance of a task in the public interest. The lawful basis used to process *special category personal data* will be for scientific and historical research or statistical purposes.

Your personal data will be processed so long as it is required for the research project. We will anonymise all personal data you provide, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

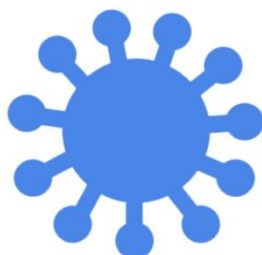
**13. Who is organising and funding the research?**

The research is led by researchers at University College London (UCL). UCL is sponsoring the research.

**Thank you for reading this information sheet and for considering taking part in this research study.**

---

## Appendix G: Participant Consent Form for Online Focus Groups



## THE COVID-19 WELLBEING STUDY

### **Participant Consent Form for the Online Focus Groups**

UCL Research Ethics Committee Approval ID Number: 7335/004

#### **Title of Study:**

*The COVID-19 Wellbeing Study*

Perceived coercion and psychological wellbeing during the COVID-19 Pandemic

#### **Department:**

Science & Technology Studies / Psychology & Language Sciences

#### **Name and Contact Details of the Researcher(s):**

Miss Josephine Harris T: [REDACTED]

Dr Veronica Ranieri T: [REDACTED]

Ms Andrea Stoltenberg T: [REDACTED]

Prof Sarah Edwards E: [REDACTED]

Prof Sunjeev Kamboj E: [REDACTED]

**Name and Contact Details of the UCL Data Protection Officer: Alexandra Potts [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)**

**This study has been approved by the UCL Research Ethics Committee: Project ID number:**

\_\_\_\_\_

\_\_\_\_\_

**Please complete this form after you have read the Information Sheet about the research.**

Thank you for considering taking part in this research. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in.

**I confirm that:**

- I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction and would like to take part in an online focus group.
- I consent to participate voluntarily in the study.
- I understand that I will be able to withdraw my data prior to my data being analysed and anonymised. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.
- I understand that my personal information (*ie age, gender, geographical location, health status*) will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing and 'research purposes' will be the lawful basis for processing special category data.
- I understand that my data gathered in this study will be stored anonymously and securely. I understand that the information I have submitted will be published as peer-reviewed publications and I can access a copy of these online or on [www.thecovid19wellbeingstudy.org](http://www.thecovid19wellbeingstudy.org). It will not be possible to identify me in any publications.
- I understand that my information may be subject to review by responsible individuals from University College London for monitoring and audit purpose
- I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.
- I understand that no promise or guarantee of benefits have been made to encourage me to participate.
- I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future



## Appendix H: Participant Consent Records

Consent records are displayed according to each group under their selected anonymous alias. The participant who did not make any posts is omitted. Note that aliases were selected to be anonymous and participants or their data cannot be identified from this information.

Group 1:

UCL Home Prospective students Current students Staff Josephine E Harris UCL

MyeXtend / My courses / COVID-19\_Wellbeing\_Study\_Experiences\_Shielding\_Group\_1 / Essential Information and Consent / CONSENT FORM / View 9 responses / Responses

### The COVID-19 Wellbeing Study: Experiences of Shielding Group 1

CONSENT FORM

Responses

Choice options	Yes: I consent to participation <input checked="" type="checkbox"/>
Number of responses	9
Users who chose this option	<ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> Affinity x</li> <li><input checked="" type="checkbox"/> Tilly Linden</li> <li><input checked="" type="checkbox"/> Hopalong</li> <li><input checked="" type="checkbox"/> Seren</li> <li><input checked="" type="checkbox"/> Quenie .</li> <li><input checked="" type="checkbox"/> Nedash</li> <li><input checked="" type="checkbox"/> Shadow .</li> <li><input checked="" type="checkbox"/> Sapphire .</li> <li><input checked="" type="checkbox"/> Toggle G</li> </ul>

Group 2:

UCL Home Prospective students Current students Staff Josephine E Harris UCL

MyeXtend / My courses / COVID-19\_Wellbeing\_Study\_Experiences\_Shielding\_Group\_2 / Essential Information / CONSENT FORM / View 7 responses / Responses

### The COVID-19 Wellbeing Study: Experiences of Shielding Group 2

CONSENT FORM

Responses

Choice options	Yes: I consent to participation <input checked="" type="checkbox"/>
Number of responses	7
Users who chose this option	<ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> Jemima .</li> <li><input checked="" type="checkbox"/> Jenny</li> <li><input checked="" type="checkbox"/> Scubacrazy .</li> <li><input checked="" type="checkbox"/> Mary</li> <li><input checked="" type="checkbox"/> Dixie</li> <li><input checked="" type="checkbox"/> Lucy Pevenie</li> </ul>

Group 3:

UCL Home Prospective students Current students Staff Josephine E Harris UCL

MyeXtend / My courses / COVID-19\_Wellbeing\_Study\_Experiences\_Shielding\_Group\_3 / Essential Information and Consent / CONSENT FORM / View 9 responses / Responses

### The COVID-19 Wellbeing Study: Experiences of Shielding Group 3

CONSENT FORM

Responses

Choice options	Yes: I consent to participation <input checked="" type="checkbox"/>
Number of responses	9
Users who chose this option	<ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> Lysander</li> <li><input checked="" type="checkbox"/> Daisy</li> <li><input checked="" type="checkbox"/> ynda</li> <li><input checked="" type="checkbox"/> Hlchlnlady</li> <li><input checked="" type="checkbox"/> Pumba</li> <li><input checked="" type="checkbox"/> Broomstick</li> <li><input checked="" type="checkbox"/> Matilda</li> <li><input checked="" type="checkbox"/> Shadowno1 .</li> <li><input checked="" type="checkbox"/> Lucy</li> </ul>

## Appendix I: 'Netiquette Guidelines': Ground-Rules Information for AVFGs

# Netiquette: )

Let's talk about netiquette!

As we are not there physically to help moderate the focus group, we ask that participants practice the rules below:

- **Respect other participants' privacy.** Do not quote or forward fellow participants' writing outside of this focus group/forum.
- **Respect the privacy of people not in the focus group.** Please don't post identifiable information about individuals not in the group, and only share your experiences.
- **Avoid sarcasm.** People who don't know you may misinterpret its meaning.
- **No spam (a.k.a. junk mail).** Please don't insert advertisements for services or individuals. Please don't post chain letters, rumours, etc.
- **Be kind.** Communicating online is unique in that there tends to be a level of anonymity between the people who are interacting. This sometimes results in individuals being more impolite than they might be in person. Please make a point to be respectful in your comments—even if you disagree or dislike someone's stance on a topic.

The focus group/forum will be **moderated twice daily** to check if participants are feeling distressed and that these rules are adhered to.

Should you become distressed by the content of the focus group, please contact [REDACTED]

## Appendix J: Useful Contacts for AVFGs

## Useful Contacts



**Should you feel distressed during the study, please contact us on**

[REDACTED]

We would also encourage you to contact your general practitioner or the Samaritans at 116 123.

For a full list of urgent and charity support organisations, please visit: <https://www.nhs.uk/mental-health/nhs-voluntary-charity-services/charity-and-voluntary-services/get-help-from-mental-health-helplines/>

**Should you encounter any difficulties during the online focus group, please contact**

[REDACTED]

**Should you have queries regarding the overall conduct of the study, please contact Sarah at**

[REDACTED]

or Sunjeev at

[REDACTED]

## Appendix K: Example illustration of initial semantic-level coding

Re: This week's main discussion: Experiences of shielding advice being paused

Perceptions of what the ending of shielding means

by [REDACTED]  
It feels different because before, we were told that shielding had paused. But this time I feel that shielding has ended. It feels like the Gov is saying that there's enough capacity for the hospitals to take us now, rather than we're being guided to shield for our own safety.

Feeling shielding lifted because hospital has more capacity for high risk sickness

Began doing some activities that feel safe e.g. shopping

Felt a little safer with vaccine rollout

by [REDACTED]  
That's how I feel too, they scare the pants off us to make sure we stay away from people so we don't get ill, now it feels like, we'll we don't care if you get it now there is a hospital bed to treat you, doesn't matter if you get really sick & end up with long covid or worse, dead... We did our best and you had hospital bed & treatment...  
What happened to prevention is better than cure...?

Cannot live life shielding forever

Perceptions about what the government lifting shielding means

Government acting too slowly

Continued to shield between shielding periods

Making ones' own rules and choices to keep safe regardless of advice

Assessing risk to guide choices

Others thinking they are paranoid

by [REDACTED]  
For me, the latest advice about not having to shield has felt more reassuring because I've had two vaccines, my husband and youngest son have had 1 vaccine each, so I definitely feel safer. I only go to the supermarket really but wouldn't venture to a pub/restaurant or busy outside area just yet. I'm sure we aren't out of the woods just yet in general but I think I've been safe during the worst of the pandemic so far. I cannot live life shielded long-term, but that's my personal preference not to strictly shield

by [REDACTED]  
This time unlike the last I feel that shielding has pretty much ended rather than been paused. Paused implied it was temporary and would be resumed when inevitably people started to die and as everyone expected the second wave was worse and the government dithered until it was too late like the first time. Shielding restarting too slowly. I just continued to shielding because if I could see it coming like a slow motion car crash why risk it?  
This time I think with the vaccines I have lowered my defences a little but I risk assess to my satisfaction. I no longer care what the advice is I don't think this is over yet. I can identify with people thinking I'm Paranoid tell them try telling that to the families who lost someone or have long covid. I'm done with being apologetic



Appendix L: Representation of Thematic Codes at Phase 4 of Thematic Analysis:  
Reviewing Themes

Parent Codes: Key Themes	Second Order Codes: Subordinate Themes	Third Order Codes	
Fear and Anxiety (relating to the threat of COVID-19)			
Perceptions and Experiences of Shielding (in the context of the wider preventative measures)	Support for policy		
	Positive Shielding Experiences		
	Psychological Challenges of Shielding		
Impact of the "High Risk" Classification	Awareness of one's own mortality		
	Identity		
	Receiving official shielding instruction		Relief
		Distress	
Managing the Challenges of Shielding (and its implications in the context of the pandemic)	Certainty of access to essentials		
	Community		Relationships
			Camaraderie
	Finding ways to cope		Prioritising self-care
			Staying well-informed
			Structure
			Value of a virtual world
Value of the outdoors			
Value of sharing stories			
Perceived Choice and Control	Sense of Choice	Felt Choice	
		Felt Lack of Choice	
	Sense of Control		
Commitment to Health-Preserving Behaviours	Balancing risk with quality of life		
	Personal circumstances that enable choice		
	Preserving Personal Safety		
	'Unofficial' Shielding		
Navigating the Choices and Perceptions of Others	Expectations		
	Feeling Invalidated		
	Impact of others' relaxed adherence to rules and guidance		Difficulty ensuring others' adherence in shared space
	Others' beliefs and understanding		
	Strained relationships		

Physical Reintegration	Employment Pressure	
	Feeling unsafe	
	Felt readiness for 'normality'	
	Gradual readjustment	
	Vaccination and Immunity	
Perceptions of the UK Government	Guidance Communications	Delay to high risk classification
		Not enough notice
		Poorly worded shielding letters
		Unclear guidance and rules
	Perceptions of the UK Government's Approach	Positive Perceptions
		The Furlough Scheme

## Appendix M: Thematic Map

Thematic map displaying final identified domains and themes and their conceptual connections. Connections within domains, themes and subthemes are illustrated in blue. Conceptual links between domains and themes are illustrated in orange.

